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A Case Study of Parental Experiences and Engagement in the Individual Educational Plan (IEP) Conference

Kevin Witherspoon
University of St. Thomas, Minnesota, kevinwitherspoon@hotmail.com

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Kevin J. Witherspoon

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We certify that we have read this dissertation and approved it as adequate in scope and quality. We have found that it is complete and satisfactory in all respects, and that any and all revisions required by the final examining committee have been made.

Dissertation Committee

Sarah J. Noonan, Ed.D., Committee Chair

Shelley Neilsen Gatti, Ph.D., Committee Member

Dave W. Peterson, Ph.D., Committee Member

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Abstract

The Individuals with Disabilities Education Act (IDEA) 2004 requires parental participation at the Individual Educational Plan (IEP) conference. This qualitative, case study examined the experiences of parents during the IEP conference to identify factors influencing collaboration between parents and school personnel. Fourteen parents described their experiences and emotions as they became involved in the special education process. Parents described their feelings at the time of their child's referral to special education services, their participation in the IEP conference, and their impressions and expectations after the IEP conference. This study identified parental experiences in three stages: initial, intermediate, and final stages corresponding to the grief and loss model adapted from the Kübler-Ross Model (1969). A central finding of this study involved parental participation, satisfaction, and engagement in the IEP conference and its dependency on the stage of grief and loss parents experienced at the time of the IEP conference. Other analytical lenses used to examine parental experiences in the IEP conference include structural role theory (Turner, 2002) and chronic sorrow (Olshansky, 1962). A second finding involves the presence of chronic sorrow (Olshansky, 1962), referring to the cyclical reaction of profound sadness and loss. The study revealed the need for helping parents through the emotional distress of having a child in need of special education services. Recommendations included training educational professionals in the areas of grief and loss to help parents manage their emotional reactions and providing information to parents regarding support groups and other resources.

Keywords: IDEA 2004, parental experiences, parental participation, IEP conference, grief and loss, structural role theory

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Table of Contents

PAGE

Table of Tables

Table Page

Table of Figures

Figure Page

Chapter 1: A Case Study of Parental Experiences and Engagement in the IEP Conference

I have served in the field of special education for 13 years as a special education teacher and assistant principal supervising special education programs. Recently promoted to director of special services, I currently oversee all special education and related services in a growing suburban school district located southeast of the Minneapolis/St. Paul Metropolitan area. Special Education is defined by the state of Minnesota as "any specially designed instruction and related services to meet the unique cognitive, academic, communicative, social and emotional, motor ability, vocational, sensory, physical, or behavioral and functional needs of a pupil as stated in the Individual Education Plan (IEP)" Minnesota Rule *[3525.0210, Subp. 42]*. Special education services provide specialized instruction or accommodations to serve those students who meet specific criteria to qualify for special education services in Minnesota.

During my 13-year career as a special educator of students with disabilities, I have worked with countless students and their parents and attended hundreds of Individual Educational Program (IEP) conferences. From the beginning of my participation as a teacher in IEP conferences, I found them to be a bit unwelcoming to parents; however, I never gave much thought to the nature and quality of parental involvement. During my informal observations of IEP conferences as a participant observer, I often found school personnel made most decisions prior to the actual IEP conference with parents. Quite often the interactions with parents resulted in approval of the already prepared plan presented to parents with no changes. When relaying evaluation information to parents about their child, school personnel simply read through testing protocols and rapidly moved through the conference. Parents rarely asked questions and when they did school personnel provided "stock" answers regarding technical data with little or no

interaction regarding the data, its interpretation, and the special education plan. The entire IEP conference typically lasted 30 minutes.

Previously, I considered the mere presence of parents at the conference to represent a partnership in the IEP process. I never seriously questioned the role of parents in the IEP conference until I met Candace. After I met Candace, I began to pay attention to what was really going on during the IEP conference.

A parent of two children with autism, Candace moved from the East Coast to my school district. During our initial phone conference, we introduced ourselves briefly and talked about her children. She told me a little bit about her sons' current educational programming, and we exchanged the proper "release of information" forms via fax; subsequently she faxed me the documents. After reading the documents, I called her back to apprise her of the educational placements we could potentially offer and to schedule an IEP conference.

We started the conference with introductions and outlined the purpose of the meeting, a process I had used hundreds of times before. Then the oddest thing happened, Candace bent over and began riffling through her oversized bag. I thought, "What is she doing?" She then pulled out two framed pictures of her sons, placed them on the table, and started talking. Candace said, "Let me tell you a little bit about John." Watching her, I noticed the pride evident both in her face and her voice as she described her sons. I never experienced this type of communication from a parent prior to meeting Candace.

After this experience I began to question the communication process with parents during the IEP conference and also to analyze my own style of communication with parents during the IEP conference. Why do some IEP conferences go so well while others do not? How do parents feel about their communication with school personnel during the IEP conference? Ultimately, I

concluded that even when there seemed to be no conflict evident, some parents still described their experiences as negative.

Statement of the Problem, Purpose and Significance

The provisions of IDEA 2004 mandate that parents be active participants in the IEP conference. Despite the provisions, observational studies indicate less than ideal parental participation, satisfaction, and engagement in the IEP conference (Garriott, Wandry, & Snyder, 2000; Goldstein, Strickland, Turnbull, & Curry, 1980; Poland, Thurlow, Ysseldyke, & Mirkin, 1982; Rock, 2000). In addition, Katsiyannis and Ward (1992) contended "many parents have little or no involvement in children's special education service" (p. 54). This was supported by Spann, Koehler, and Soenksen (2003) who noted, "despite its need and importance many parents have little or no involvement in special education" (p. 228). Parental experiences before, during and after the IEP conference may impact their participation and willingness to partner with school personnel.

When schools and families become partners, they create conditions that allow for ongoing problem solving and collaboration that benefits everyone" (Christenson, Palan, & Scullin, 2009, p. 10). In order for a genuine partnership to exist between parents and school personnel when making educational planning decisions for students, educators and service providers must understand what factors influence why parents either do or do not actively participate in the IEP conference. Factors hindering or promoting parental participation and shared decision-making must be identified. Directors of special education services and teachers may offer better services and encourage parental involvement with improved communication between parents and school personnel during the IEP conference.

The purpose of this case study was to examine the experiences of parents before, during, and after the IEP conference to understand how effective communication might improve the collaboration and partnership needed to serve students receiving special education services. This is important because increased parental participation and communication are essential in developing meaningful educational plans to improve special education services for students.

Parental participation at IEP conferences increases the educational outcomes of children (Halle, Kurtz-Costes, & Mahoney, 1997; Desimone, 1999). One of the barriers to participation has been the degree of participation and satisfaction a parent receives from attending the IEP conference. Valle and Aponte (2002), and Vaugh, Harrell, & Lasky, (2001) reported communication breakdowns may be attributed to parental participation and engagement in the IEP conference. This study examined how to foster genuine partnerships between parents and school personnel to make better educational planning decisions for students with disabilities. The information gleaned from this study may contribute to the research associated with parental participation and collaboration in the IEP process between parents and school personnel.

Research Question

How do parents experience the IEP conference as advocates for their children and partners involved in planning and supporting their children's educational program? How do these experiences affect their participation with regard to their child's educational plan and program?

1. How does the experience of the IEP conference affect parents' views of school personnel and influence their decision to actively participate in planning and supporting their child's educational plan and program?
2. How does the nature of the communication with school personnel promote or hinder parental participation in the IEP conference?
3. How do parents experience and evaluate their communication interactions with school personnel during the IEP conference?

Parental participation at IEP meetings increases the educational outcomes of students (Halle, Kurt-Costes, & Mahoney, 1997; Desimone, 1999). One of the barriers to parental participation has been the degree of participation and satisfaction a parent receives from attending the IEP conference. Valle and Aponte (2002), and Vaugh, Harrell, & Lasky, (2001) reported communication breakdowns may be attributed to parental participation and engagement in the IEP conference. I examined factors influencing parental participation and identify strategies for fostering genuine partnerships between parents and school personnel to make educational planning decisions for students with disabilities. The information gleaned from this study may contribute to the research associated with parental participation in the IEP process as well as collaboration between parents and school personnel.

Overview of Chapters

I introduced the study and describe my interest and background regarding special education and parental engagement in the IEP conference in chapter one. In chapter two, I summarized findings from a review of the literature regarding parental experiences and engagement in the IEP conference. I described factors affecting communication, participation, legal requirements, parental perceptions, being heard, and cultural influences. I also described theories used to analyze the study, including grief and loss theory (Lamb, 1988; Kübler-Ross and Kessler, 2005), structural role theory (Turner, 2002; Zigurs & Kozar, 1994), and chronic sorrow (Olshansky, 1962) in chapter two.

In chapter three, I described methods used to conduct my qualitative case study. I explained why I chose qualitative research and case study research, describing the general approach and procedures used to conduct my study. This included gaining Institutional Review Board permission, recruitment and selection of participants, data collection methods and analysis, discussion of validity for qualitative research, and protecting confidentiality. I then described my findings and analysis in chapters four, five, and six.

In chapter four, I describe parents' experiences when their child has been referred for special education services, distinguishing between medical diagnosis and educational determination. I then provide my analysis through the use of grief and loss theory (Lamb, 1988; Kübler-Ross and Kessler, 2005).

A description of parental feelings is provided regarding how parents actively explore the IEP process and its ramifications for their child appears in chapter five. This includes the preparation for and attendance at the IEP conference. I also provide an analysis using the grief

and loss model (Haley, Hammond, Ingalls, & Romaro Marin, 2013), originally conceptualized by Kübler-Ross and Kessler (2005).

In chapter six, I identify parental feelings after the IEP conference. This includes parents' analysis of the conference, how they evaluate their communication with school personnel, what made them feel satisfied when leaving a meeting, and recommendations for increasing participation. Additionally, I describe parents' hopes for their children's future. I analyze the final stage, interpreting how grief and loss theory shows differences in the way parents resolve their grief (Lamb, 1988; Kübler-Ross and Kessler, 2005). Regarding the parental resolution of their experience, I introduce and analyze data concerning "chronic sorrow" (Olshansky, 1962), a condition-affecting parents of children with significant disabilities.

I provide a summary of my findings and their implications for identifying strategies for improving collaboration with parents and school personnel during the IEP conference, and also recommend changes in practice based on my findings in chapter seven. I close with a description of limitations in my study.

I begin with a definition of terms and then review the literature on parental experiences and engagement in the IEP conference and introduce the analytical theory used in this study.

Definition of Terms

Ambiguous Loss*:* when a loss is not clearly defined or is not recognized or in cases where the griever is not recognized as legitimate (Boss, 1999).

Attention-Deficit Hyperactivity Disorder (ADHD): a behavioral condition that makes focusing on everyday requests and routines challenging (www.apa.org).

Autism Spectrum Disorder (ASD): a disability category characterized by an uneven developmental profile and a pattern of qualitative impairments in several areas of development,

including social interaction, communication, or the presence of restricted, repetitive, and stereotyped patterns of behavior, interests, and activities. ASD may include Autistic Disorder, Childhood Autism, Atypical Autism, Pervasive Developmental Disorder Not Otherwise Specified, Asperger's Disorder, or other related pervasive developmental disorders (*Minnesota Rule [3525.1325]*).

Chronic Sorrow: as identified by Olshansky (1962), differs from the time-bound grief in that the emotional responses to a loss reoccur for as long as the cause of the grief is still present. He notes that chronic sorrow is not continuous, but that there are peaks in the re-experience of the grief stages.

Deaf and Hard of Hearing (D/HH): a "diminished sensitivity to sound, or hearing loss, that is expressed in terms of standard audiological measures" (*Minnesota Rule* [3525.1331]).

Developmental Cognitive Disability (DCD): "a condition resulting in significantly below average intellectual functioning and concurrent deficits in adaptive behavior that adversely affects educational performance and requires special education and related services" (*Minnesota Rule* [3525.1333]).

Diagnostic and Statistical Manual of Mental Disorders (DSM): this manual published by the American Psychiatric Association covers all mental health disorders for both children and adults. It also lists known causes of these disorders, statistics in terms of gender, age at onset, and prognosis as well as some research concerning the optimal treatment approaches. Mental health professionals use this manual when working with patients to better understand their illness and potential treatment (www.apa.org).

Down Syndrome: a genetic disorder caused when abnormal cell division results in extra genetic material from chromosome 21. This generic disorder, which varies in severity, causes lifelong

intellectual disability and developmental delays, and in some people it causes health problems (mayoclinic.org).

Education for All Handicapped Children Act: the predecessor to Individuals with Disabilities Education Act (IDEA) that arose from federal case law holding the deprivation of free public education to disabled children constitutes a deprivation of due process.

Emotional or Behavioral Disorders (EBD): "an established pattern of one or more of the following emotional or behavioral responses:

A. withdrawal or anxiety, depression, problems with mood, or feelings of self-worth;
B. disordered thought processes with unusual behavior patterns and atypical communication styles; or
C. aggression, hyperactivity, or impulsivity" (*Minnesota Rule* [3525.1329]).

Federal Setting 03: student receives special education services outside the regular classroom more than 60% of the school day.

Grief: the physical, psychological, and social reaction to the loss of something or someone important to individuals (Hooyman &Kramer, 2006).

Individual Education Plan/Program (IEP): a written statement for each pupil that is developed, reviewed, and revised in a meeting and includes: a statement of the pupil's present levels of educational performance, measurable annual goals, statement of special education and related services and supplementary aids, participation with non-disabled peers, modification, and transition services.

Individual Education Plan (IEP) Team: "a group of individuals that must include: parents, at least one regular education teacher, at least one special education teacher, and an administrative designee" (*Minnesota Rule 3525.2900]).*

Individuals with Disabilities Education Act (IDEA): a United States federal law governing how states and public agencies provide early intervention, special education and related services to children with disabilities. It addresses the educational needs of children with disabilities from ages birth to 21.

Obsessive-Compulsive Disorder (OCD): an anxiety disorder in which people have unwanted and repeated thoughts, feelings, ideas, sensations (obsessions), or behaviors that make them feel driven to do something (compulsions) (http://nimh.nih.gov).

Other Health Disability (OHD): "having limited strength, endurance, vitality, or alertness, including a heightened or diminished alertness to environmental stimuli, with respect to the educational environment that is due to a broad range of medically diagnosed chronic or acute health conditions that adversely affect a pupil's educational performance" (*Minnesota Rule* [3525.1335]).

Public Law 94-142 also known as P.L. 94-142: (Education for All Handicapped Children Act), the name for law preceding IDEA.

Role Theory: a term used to describe a set of related theories that all seek to explain how social behavior is organized and given meaning for individuals and groups in terms of roles (Turner, 2002).

Special Education: "Any specifically designed instruction and related services to meet the unique cognitive, academic, communicative, social and emotional, motor ability, vocational, sensory, physical, or behavioral and functional needs of a pupil as stated in the Individual Education Plan" (*Minnesota Rule [3525.0210, subp. 42].*

Structural Role Theory: a lens for understanding the nature of roles in team settings. If each member of a team has a designated role (e.g. teacher, principal, parent, psychologist) then the

group will place expectations on each individual to behave in ways that are consistent with their role (Turner, 2002).

Visually Impaired: "a medically verified visual impairment accompanied by limitations in sight that interfere with acquiring information or interaction with the environment to the extent that special education instruction and related services may be needed" (*Minnesota Rule* [3525.1345]).

Chapter 2: Review of Literature

I conducted a review of literature to locate scholarly studies on parental experiences during the IEP conference and identify gaps in the literature regarding my research question. I divided my findings into four sections, beginning with parental experiences at the IEP conference. This section incorporates observational studies, testimonies, and surveys of parents. The second section addresses the importance of communication and participation between parents and school professionals as well as the barriers to successful communication and participation. In the third section I describe empirical studies pertaining to parental participation and decision-making. I conclude with a section on parental perceptions of the IEP conference including cultural influences. To provide background and context for my study, I begin with a brief description of the history of special education.

History of Special Education

Almost 40 years ago, Congress passed the hallmark Education for All Handicapped Children Act of 1975, commonly referred to by educators as P.L. 94-142, which "guaranteed a free and appropriate public education [FAPE] to each child with a disability in every state and locality across the country" (Office of Special Education and Rehabilitative Services (OSERS), 2007, para. 15). The law was designed to improve access to education for children with disabilities and had four general purposes:

1. to assure that all children with disabilities have available to them…a free and appropriate public education which emphasized special education and related services designed to meet their unique needs
2. to assure that the rights of children with disabilities and their parents…are protected
3. to assist States and localities to provide for the education of all children with disabilities
4. to assess and assure the effectiveness of efforts to educate all children with disabilities. (OSERS, 2007, para. 17)

In addition to providing FAPE to children with disabilities, P.L. 94-142 also included provisions ensuring that parents were involved in the decisions made by the school for the child both in terms of being able to provide input into the educational plan and giving parents due process rights to dispute any decisions with which they did not agree. This was the beginning of parental involvement in the education of children with disabilities.

Despite the mandates for parental participation within the original legislation, Congress believed that the role of parents within the special education process needed to be strengthened (Miles-Bonart, 2002; Rock, 2000; Silverstein, Springer, & Russo, 1992; Smith, 2001). As a result, in 1990 the Individuals with Disabilities Education Act (IDEA) replaced P.L. 94-142. Among other improvements made to the existing law were the provisions of educating disabled children with their non-disabled peers "to the maximum extent appropriate" (IDEA, 1990, sec. 612), and a provision for greater family involvement in the educational process for their children.

The Individuals with Disabilities Act (1997) focused on the development of the individual education plan for all children with disabilities and maintained that parents be involved in all aspects of the child's education including the process of referral for special education and the development of the IEP. Additional requirements specified in IDEA (1997) included obtaining written informed consent for evaluations, mandating inclusion of parents at all IEP conferences, providing parents with a copy of their rights, and ensuring that procedural safeguards are in place and acknowledged by parents.

The most recent special education law reenactment, the Individuals with Disabilities Education Improvement Act 2004, again addressed parental rights. These rights included access to educational records, and prior written notice to parents in their native language for any

changes to the child's plan. The significance was the change in priority making parents partners rather than observers in the IEP process.

Parental Participation

Both P.L. 94-142 and IDEA 2004 included provisions to increase parental involvement in the child's education. These provisions have had a positive effect on parental participation in IEP meetings (Goldstein, Strickland, Trumbull, & Curry, 1980; Martin, Marshall, & Sale, 2004). However, there is ample evidence that such parental participation is not yet at the level that researchers and educators feel is appropriate (Gilliam & Coleman, 1981; Katsiyannis & Ward, 1992; Lynch & Stein, 1982; Spann, Kohler, & Soenksen, 2003).

Parent and family involvement and engagement in education are now widely accepted as critical to inclusive school practice and as strategies for supporting higher achievement for increasingly diverse student populations (Bouffard & Weiss, 2008; Epstein, 2001a, 2001b; Pushor & Murphy, 2004). Researchers in a number of studies have cited the importance of parental involvement. In one example, Fylling and Sandvin (1999) noted parental involvement in a child's education is an important variable in the "effectiveness of schools and the attainment of children" (p. 145).

An investigation by Spann et al. (2003) agreed with the previous research regarding parental involvement with school personnel. When it comes to understanding the importance of parental involvement in a child's education, specifically children with disabilities, the research suggests the positive effect of such involvement (Spann et al., 2003). They noted that prior to the 1980s parents were dependent on school professionals for support both for an understanding of special education and their child's placement, and providing emotional support during the

process (Spann et al., 2003). In their review of literature, Spann et al. (2003) found after IDEA 1997, parents became equal partners in the special education process.

> Greater parent participation leads to a host of positive outcomes for children with special needs, including greater generalization and maintenance of treatment gains (Koegel, Koegel, & Schreibman), greater continuity in intervention programs (Bailey & Wolery), higher levels of parent satisfaction (Stancin, Reuter, Dunn, & Bicklett), and more effective strategies for resolving problems. (Newman & Wehlage; as cited in Spann et al., 2003, p. 228)

Understanding the historical context is significant in examining the parental perspective and the vital importance of their involvement in the IEP conference. Historically, the role of parents of children with disabilities was not given equal weight with the school personnel providing services to their children (Sonnernscein, 1981). The plight of parents of children with disabilities to serve as active and equal team members during the IEP conference has shaped current legislation mandating their participation and inclusion in the IEP experience.

Parental Experiences at the IEP Conference

Parent participation serves as a key element in the IEP conference (Valle & Aponte, 2002). Parents must have the opportunity to contribute their unique perspective of the child at home (Swick, Hobson, & Raymond, 1980). To achieve a successful conference, teachers and specialists must communicate clearly and effectively with parents and make them feel they are important members of the team (Swick et al., 1980). Information shared by teachers and specialists may be threatening, anxiety producing, or intimidating to parents if it is not presented in the proper atmosphere (Swick et al., 1980). If parents feel uneasy or overwhelmed by the conference, they may not be willing or able to share important information about their child (Swick et al., 1980). Yanok and Derubertus (1989) found parents and teachers are the key stakeholders in the development of the IEP. However some parents feel ill equipped to address the special learning needs of their children, and out of frustration, they relinquish the

responsibility of their child's education to educational professionals (Sheehey, 2006; Yanok & Derubertus, 1989).

Swick et al. (1980) concluded the IEP conference provides an excellent opportunity for parents and teachers to share their resources in developing the best quality education program for a child. "The most productive IEP conferences are conducted in physical settings that invite discussion and exchange of ideas between parent and teacher" (p. 145). Furthermore, it is apparent that parents must have the opportunity to share and contribute their perspective, and parents must feel they are important members of the team to achieve the best educational outcome of the conference.

Congress intended previous federal mandates to strengthen the role of parents and encourage parents and teachers to resolve their differences using non-adversarial venues (Bateman & Linden, 1998). IDEA 1997 and subsequently 2004 increased active parental representation by expanding the preexisting IEP participation mandate to legislate parents to be active participants in the IEP conference (Rock, 2000). However, observational studies indicate less than ideal parental experiences. Rock (2000) described the traditional IEP meeting as a "meaningless ritual" (p. 32) in which teachers dictate the prescribed educational program and then pass the ceremonial pen to parents to secure signatures.

Goldstein et al. (1980) observed IEP meetings with parents of mainstreamed children in an elementary school. Fourteen meetings were observed, 11 involving children being initially considered for special education. During this study, an observer coded the contents of the meeting in an attempt to delineate the frequency of parent involvement during the meeting. A questionnaire was also developed and completed by the resource teachers, parents, classroom teachers, principals, and other participants to determine the participants' satisfaction with the

meeting. Results indicated no significant differences among groups with regard to their satisfaction with the IEP conference proceedings.

"The 14 IEP meetings lasted an average of 36 minutes, with a minimum of six minutes to a maximum of 72 minutes. The mean number of participants at the meeting was 3.7, with a range of two to six participants" (Goldstein et al., 1990, p. 279). The percentage of conferences attended by the resource teacher was (100%), parent (100%), classroom teacher (43%), evaluator (29%), principal (21%), as well as other participants attending only a few meetings. Observation concerning the communication during the IEP meeting revealed that the special educators talked twice as much as parents, with the mean speaking citations of resource teachers being 9.6 and parents 4.6 (p. 280).

Findings from the Goldstein et al. (1990) study agreed with findings from Sonnernschein's (1981) earlier study, which showed parents' opinions were not given weight equal to that of the professionals. Sonnernschein described the disappointing role of parents in IEP conferences, "Too frequently, observational and suggestions made by parents are given little weight and concerns are dismissed without appropriate investigation" (p. 64). Findings from this study are consistent with those of Underwood (2010). Underwood confirmed varying degrees of parents' involvement and engagement in developing the IEP for their children:

> Eighteen of the 31 parents in the study reported that they were actively or very much involved in the development of the IEP for their children. However, 13 of the parents reported that they were not at all, rarely, or only somewhat involved in developing the IEP. (p. 27)

A similar study by Garriott, Wandry, and Snyder (2000) distributed 96 questionnaires (84 were returned) to investigate the perceived levels of involvement and satisfaction with the IEP conference.

> Results of the questionnaire revealed that 45% of the respondents felt that they were treated in a fair and equitable manner, 27% indicated usually, and 27% expressed sometimes or never. Additionally, 46% of respondents indicated that they always felt that they had been given ample and direct input in the formation of the IEP goals and objectives for the child, with 24% indicating usually, and 27% indicating sometimes or never. (p. 40)

Findings from Fish (2008) are consistent with those of Garriott et al. (2000). Fish (2008) revealed it is important for educators to build positive relationships with parents during IEP meetings (p. 13). "The majority of participants responded favorably by reporting that their overall IEP meeting experiences had been positive" (p.13).

In addition, Poland, Thurlow, Ysseldyke, and Mirkin (1982) reported "that 79 of 100 surveyed Directors of Special Education acknowledged that team meetings for the purpose of discussing eligibility and placement were held *before* meeting with the parent" (italics in original, p. 176). The directors also admitted IEPs were mostly completed without parental input. The findings appear to contradict what Congress intended in the passing of IDEA, and excluded parents from serving as active and equal team members during the IEP conference.

Parents often sense that their comments are not as valued as those of the educational professionals during the IEP conference, and educational professionals often make IEP team decisions before the actual meeting (Poland et al., 1982). The National Council on Disability (1995) heard testimony from more than 400 parents and family members of children with disabilities and documented that "parents continued to be presented with completed IEPs by school personnel," thereby feeling "largely left out of the process" (p. 11).

Engel (1993) confirmed, in addition to feeling left out of the IEP process, parents engaged in the process reported largely unsatisfying experiences.

> There is an asymmetry to the IEP conference…One party enters the discussion with control over resources while the other only has needs and rights…The negotiating process for the parents is, therefore, a matter of attempting to bargain for resources by citing needs—a frustrating and sometimes humiliating process. (pp. 820-821)

To further associate this unbalance of power, Malekoff, Johnson, and Klappersack (1991) surveyed more than 100 parents of children with learning disabilities. They reported "over half of the parents indicated that they were initially confused" about their child's diagnosis and the test results and recommendations were "not helpful" (p. 420). In another example, Engel (1993) commented on the parental experiences in the special education committee meeting

> These professional members of the CSE use language to discuss disabilities that is foreign to most parents…Although it is their child who is being discussed, it does not seem like their child…Their own knowledge systems seem trivial and 'unscientific' in comparison to the knowledge systems of professionals. The parents sense that their comments carry less weight in the CSE meeting because they are not couched in the language of the professionals and because the parents' close relationship to their child makes them seem overly subjective. (p. 800)

Moreover, Taber (2007) argued the high level of reading needed in reviewing documents may not help parents access the information needed:

> One half of the "parent's rights" document distributed to parents whenever a meeting is held on behalf of their child with disabilities is written at a college reading level. This means that more than 90 percent of parent's rights documents are too difficult for the average person to read and understand. (p. 23)

In the next section, I review the literature on the importance of communication between parents and school personnel.

Importance of communication and participation. Communication between parents and school professionals aids in developing collaborative partnerships in the best interest of children (Epstein, 2001; Turnbull & Turnbull, 2001). Ulrich and Bauer (2003) maintained mandatory communication between parents of children with disabilities and educational

professionals exhibits best practice. "Yet parents and professionals do not always agree what would be in the best interest of the family and child" (p. 20). Additionally, Dabkowski (2004) claimed communication between parents and schools was widely accepted as an important component of good practice in serving children with disabilities and in developing IEPs.

Communication is a process by which people send and receive information. Because of the special needs of family members with exceptionalities, many families and professionals have frequent opportunities to communicate with each other. Unfortunately, families and professionals often perceive communication as less than adequate (Sonnenschein, 1981; Vaughn et al., 2001). Turnbull, and Turnbull (1990) described the importance of effective communication with families:

> If we are to meet the challenge of interacting with families in meaningful ways, then we must find ways to transform inadequate communication among families and professionals into communication that is open, genuine, and meaningful. When families and professionals communicate openly with one another, a true partnership is formed. (p. 143)

The dynamic communication process between parents and school personnel during the IEP conference requires a great deal of collaboration, mutual respect, and trust in order to achieve educational decisions and positive outcomes on behalf of the child with a disability (Rock, 2000). Creating opportunities for increased parental participation and decision-making begins long before the actual IEP conference is held. It begins by laying a foundation built on teachers engaging in activities that communicate sensitivity, trust, respect, and acceptance to parents (Rock, 2000). This dynamic may at times include differing notions of the expectations of IEP team members. Lipsky (1985) found most often the communication between parents and professionals is anything but honest and complete; professionals often believe parents are too emotional or insufficiently knowledgeable to participate effectively in the decision-making

process. While Swick and Hobson (1980) insisted on the importance of authentic communication:

> Remember, IEP conferences are conducted by people. People make mistakes, get angry, and sometimes overreact to situations, but above all want to grow as individuals who are valued by others. The parent-teacher-specialist relationship can produce the most meaningful results when those involved use good communication skills. (p. 144)

Lindle (1989) suggested communication needed to be pleasant, yet open and to the point. When critical issues are presented in a clear, non-ambiguous manner, misunderstandings are minimized and issue resolution is more likely. Fundamental communication skills effective in promoting good communication include active listening, reflection, clarification, and summarization (Perl, 1995). Active listening involves listening in an open, nonjudgmental manner - actually hearing what the other party wants to share. Reflection is a technique used to convey understanding as the listener tries to put into words the affective nonverbal cues behind the speaker's words such as facial tension and hand wringing. Reflection demonstrates recognition and understanding of the issue being discussed by acknowledging the speaker's feelings. Clarification, useful to explain speakers' meanings when their statements lack cohesion or a clear focus, restates the content of what was said. This technique helps to eliminate ambiguity and helps to ensure mutual understanding (Perl, 1995).

A variety of communication patterns and multiple viewpoints may lead to miscommunication between parents and school personnel during the IEP conference (Lindle, 1989). A study by Lindle (1989) demonstrated how misunderstood cues may result in building mental and/or emotional barriers between parents and professionals. The survey revealed school personnel strongly believed that when teachers communicate with families in a professional, business-like manner they gain the respect and support of the parents; whereas, parents may view

professionalism on the part of teachers and staff as undesirable. "Parents mentioned their dissatisfaction with school people who are 'too businesslike,' 'patronizing,' or who 'talk down to us'" (Lindle, 1989, p. 2). The importance of examining the issue of communication barriers between parents and school personnel cannot be overstated.

Communication between parents and school personnel may be hindered by authoritarian styles of communication, and cultural differences. Swap (2003) related this phenomenon to the establishment of a compulsory education system, which remains hierarchically organized and managed. Swap argued the educational system has led to an authoritarian style of communication both within schools and between schools and homes. Over time, this has resulted in parents becoming more dependent and passive in relation to schools (Mannan & Blackwell, 1992). For at-risk families, the feelings of alienation and powerlessness experienced in their everyday lives are often brought to their most potent realization when dealing with school professionals (Winters, 1993). Since families of lower socioeconomic levels also tend to value conformity rather than autonomy and self-direction, authority-based forms of communication between teachers and parents only serve to reinforce pre-existing feelings of incompetence, inferiority, and helplessness (Swick & Graves, 1993). Furthermore, Leyser (1985) and Stein (1983) identified work and language/communication difficulties as barriers preventing parents from participating in their children's special education programs.

Cultural differences between "middle class" schools and many at-risk homes, combined with a lack of teacher training, led to multiple opportunities for miscommunication and misperceptions (Coleman & Churchill, 1997; Swick, 1993; U.S. Department of Education, 1997). The literature from Coleman and Churchill (1997) indicated parents from low-income families are as supportive of the family involvement as parents with higher income levels, but

may differ in where they are willing or able to be involved in their child's education. Likewise, Shepard, McKinney, and Trimberger (1999) concluded, "Parental hesitancy about contacting schools or becoming more involved is often directly related to feelings of insecurity or a lack of knowing how to communicate effectively with the 'school culture'" (p. 17). These differences contribute to miscommunication between parents and school personnel.

Rock (2000) reviewed literature regarding parental participation, and found researchers have focused on cultural insensitivity, ignorance, and miscommunication exacerbating traditional barriers impeding parental participation (p. 32). In her review, Rock summarized barriers to collaboration and participation identified by previous researchers, including, menu-driven district approaches (Sileo et al., Voltz), parental "tracking practices" (Voltz), reluctance to explore culturally diverse values, (Harry, Sileo et al., Voltz) "teachers know best" mindsets (Sileo et al.), lack of diversity in the teacher work force (Sileo et al.), and parental mistrust due to minority overrepresentation rates in special education programs (Harry; as cited in Rock, 2000, p. 32). Rock (2000) argued providing teachers with the tools and supports to create opportunities for active parental participation may balance the scales in the IEP development.

Shepard et al. (1999) further described the inequities between parents and school personnel and concluded:

> Parents often shut down and withhold further active participation after they receive negative feedback for their input. Additionally, hearing school representatives support each others' input and ideas with positive comments can lead a parent to feel that his or her input is of a lesser quality. (p. 19)

This feeling of inequality hinders parental engagement and participation.

Parental participation and decision-making. Parental involvement is a key to success. Children performed better academically and socially when their parents and families were involved with educators (Christenson & Cleary, 1990). Keith, Keith, Troutman, Bickley,

Trivette, and Singh (1993) have found these strong effects to be independent of family socioeconomic background variables. Children, regardless of the social or economic circumstances prevailing in a community, do better in school when parents have meaningful connections with school. The view that parent involvement and engagement will improve student outcomes has particular implications for parents of children with Individual Education Plans (IEPs). Underwood (2008) stated parents of children with IEPs are expected to participate in development and monitoring of the plan, as well as in meetings to set up the plan. Seeley (1985) argued the critical contribution to success in school came neither from the home nor the school alone, but from the dynamic relationship between them. According to Skinner (1991), parental participation in IEP conferences should be increased for at least two important reasons.

> First, parents are an extremely valuable source of information about their child. Parents can describe behavior patterns, medical history, and they possess information about potential reinforcers that is not readily obtainable from other sources. Second, if academic and social behavior changes are going to occur and generalize across environments, collaborative consultation between parents and teachers is essential. The realities of IEP conferences fall far short of true collaborative consultation. (p. 286)

Next, I describe the role of parents in the IEP conference as passive recipients of information.

Although the federal mandates have clearly presented the legal nature or status of parental participation and decision making, the translation from statutory and regulatory provisions to everyday practice has been plagued with difficulties (Rock, 2000). For more than two decades educational researchers have investigated this topic. These investigations revealed many parents view themselves as "uninvolved" in their child's education (Gilliam & Coleman, 1981; Lynch & Stein, 1982). Typically, teachers make educational decisions, and parents give consent (Harry, 1992; Healy, Keesce, & Smith, 1985).

Most parents do not participate actively during IEP conferences. They spend the majority of their time listening to professionals (Goldstein et al., 1980). Gilliam and Coleman (1981)

found the main contributors and most persuasive decision makers during the IEP conference were the psychologists or teachers who bring hard data to the meeting. In a three-year longitudinal study of low-to-middle income African American parents whose children were placed in preschool special education, Harry, Allen, and McLaughlin (1995) found parents consistently described their role in IEP conferences as passive recipients who signed papers.

Valle and Aponte (2002) reviewed learning disability literature and found a routine disqualification of parents' voices by professionals as a major obstacle to authentic collaboration.

> In light of the unprecedented emphasis on parental involvement under the Education for All Handicapped Children Act, researchers in the late 1970s and early 1980s began to study the integration of parents into the special education decision-making process. The results of these studies consistently exposed less than optimal participation of parents. Hoff, Fenton, Yoshida, and Kaufman's (1978) interviews of parents of children with mild handicaps revealed that in all phases of decision making, parents demonstrated accurate perceptions of team decisions only 50% of the time. Parents consistently indicated confusion or lack of knowledge about their rights under IDEA. (p. 470)

Obstacles to parental participation and decision-making. Several barriers decrease the probability of active parental participation in the IEP conference. These barriers include: parental feelings of intimidation (Flynn, 2006; Smith, 2001; Smith, Gartin, Murdick, & Hilton, 2006; Turbull & Turnbull, 1986;), pre-existing educational rituals (Harry, 1992), professional preparation (Turnbull & Turnbull, 1986), and compliance with federal law (Valle & Aponte, 2002).

A variety of factors may occasion parents to feel intimidated during IEP conferences, for example, a feeling of little decision making power, being outnumbered by professionals, and guilt feelings related to the cause of their child's exceptionality (Flynn, 2006; Smith, 2001; Smith, et al., 2006; Turnbull & Turnbull, 1986). Attending an IEP conference for a child may be an intimidating experience for even the most knowledgeable parent. Parents often perceive an

individualized education program (IEP) conference as a meeting with an all-powerful school staff whose only purpose is to tell them about the shortcomings and failures of their child (Gilliam & Coleman, 1981; Klingner & Harry, 2006; Losen & Losen, 1985; Sheehey, 2006). Goldstein (1993) offered ideas for changing this perception:

> It is understandable that parents might be uncomfortable about attending such a conference and might be inclined to say little if they did attend. I have developed several specific and easily developed practices that a school staff can implement to stimulate active parent involvement in a conference. The goal is to have parents become fully participating members of the IEP team. Suggestions for encouraging parent involvement:
>
> 1. Contact parents personally before the meeting.
> 2. Have a school staff member greet the parents.
> 3. Avoid eating during the conferences.
> 4. Appoint an "interpreter."
> 5. Videotape or audiotape a few conferences. (p. 60)

McLoughlin (1978) argued parents' main responsibility is to be parents, not clinicians, educators, or therapists. However, it is certainly feasible and desirable to respect the primary role of the parents while concurrently increasing their active participation in the IEP process.

Many professionals enter IEP conferences with preconceived notions of the skill-set of parents and continue to perpetuate existing rituals (Skinner, 1991). "Many professionals enter IEP meetings assuming that parents have the knowledge and skills to participate fully. This assumption is usually false, especially considering the heterogeneous population of parents" (p. 287). Due to ignorance and pre-existing educational rituals, many teachers and systems engage in culturally insensitive practices serving to further alienate parents, rather than to empower participation (Harry 1992; Quiroz et al., 1999; Sileo et al., 1996; Volz, 1994).

Professional preparation programs for pre-service special education teachers may not be adequate in focusing on communicating and creating partnerships with parents (Turnbull & Turnbull, 1986). Turnbull and Turnbull (1986) found the primary focus of many pre-service and

in-service special education teacher training programs related to parent participation in IEP conferences were on legal issues as opposed to decision making and communication skills. Few teacher education programs provide adequate training in these latter areas (Chavkin & Williams, 1988). Thus, it should come as no surprise that professionals, especially teachers, frequently do not possess adequate consultation skills needed to encourage parental participation in IEP meetings (Skinner, 1991). One explanation for this failure of partnership between parents and teachers may deal directly with federal law.

> Perhaps the public schools' uneasiness about compliance with federal law in these new procedures in part explains the overemphasis on paperwork, to the detriment of relating to parents. Perhaps the awkwardness of sharing decision making with parents within traditionally bureaucratic system in part explains the position of passivity imposed in parents. (Valle & Aponte, 2002, p. 472)

Adherence to federal law in this case, may only benefit the relationship between parents and school personnel.

Parental perceptions of the IEP conference. The communication process during the IEP conference between parents and school personnel is an intricate relationship (Turnbull & Turnbull, 2001). Both parents and school personnel enter into the conference with preconceived expectations regarding communication. The IEP conference sets the stage for fostering collaborative relationships between parents and school professionals, yet their perceptions of this meeting may differ (Ulrich & Bauer, 2003). Even when no conflict is evident, parents' perceptions of the IEP conference often differ from that of school personnel. This dichotomy entails traumatic and confusing experiences, discrepant views of the child's needs, an atmosphere of adversity, and lack of an equal voice. These perceptions are exacerbated when cultural factors are present (Turnbull & Turnbull, 2001).

Stoner, Bock, Thompson, Angell, Heyl, and Crowley (2005) concluded from studying parents' perceptions that all participants perceived their children's initial IEP meeting had been traumatic, confusing, and complicated, and their perceptions led to dissatisfaction with the special education system. Stoner et al. (2005) summarized their research by concluding, "It is vital that education professionals understand the perspectives of the parents of the children whom they serve. The key to this understanding is open communication, effective intervention practices, and service delivery that meet the needs of the child" (p. 49).

Kalyanpur, Harry, and Skrtic (2000) found educational assessment expertise not parents' anecdotal reports more heavily influenced decision-making during an IEP meeting. "Collaborative relationships often failed to exist particularly for families of low socioeconomic status and cultural diversity" (p. 129). In fact, parents' perceptions of initial IEP conferences had been traumatic, confusing, and complicated; parents were largely dissatisfied with the special education system, and educational assessment expertise took precedent over parents' reports (Kalyanpur et al., 2000; Stoner, et al., 2005). However, Fish (2006) contended the majority of parents surveyed believed their overall IEP experiences were positive. "Of participants, 47% agreed and 16% strongly agreed, whereas 12% disagreed and only 4% strongly disagreed" (p. 10). He concluded that by treating parents equally during IEP meetings, educators created fewer adversarial and intimidating experiences for parents of students with disabilities.

Having an equal voice regarding their child's education enhanced parents' abilities to influence the process of obtaining quality services for their child. (Fish, 2006). In addition, the findings by Gordon and Miller (2003) created an interesting dichotomy. They found that although 96.6% of parents felt they were important members of the IEP team and 82.1% also felt positively about the decisions made during the IEP meeting, their findings revealed parents'

assessment of special education programs were not based on objective data (p. 5). "These findings continue to raise questions about the validity of parents' perceptions and consequently of their ability to be equal participants in assessing and developing their children's services" (p. 10). Describing the importance of parental participation and accountability, Gordon and Miller (2003) explained participation allows parents to be accountable for their children's education. Until this happens, they will be minor contributors, not full team members of the IEP process.

Dealing with Adversity

Much has been written about parent-school partnerships and collaboration, but, professionally, little is written about how to maintain collaboration in the face of adversity (Lake & Billingsley, 2000). The purpose of Lake and Billingsley's (2000) study was to identify which factors escalated or deescalated parent-school conflict from the perspective of parents of children with disabilities, school administrators, and mediators. Parents identified the following eight: discrepant views of a child or child's needs, knowledge, service delivery, constraints, valuation, reciprocal power, communication, and trust (Lake & Billingsley, 2000).

Miles-Bonart (2002) found direct positive relationships existed when professional etiquette and procedural factors were examined as sole indicators of satisfaction. Other factors influencing participants included: lower levels of satisfaction among parents whose children have Physical/Health Impairments, the important relationships between effective communication and satisfaction, and parent dissatisfaction due to the absence of school personnel in IEP meetings (Miles-Bonart, 2002). Gray's (2005) study was in agreement with the Miles-Bonart (2002) study, suggesting there is a strong relationship between parent satisfaction and positive communication between the parents and the school. "However, the study found little connection between parent satisfaction and parent involvement" (Gray, 2005, p. 85). Next, I explore the

realities of a lack of communication between parents and school personnel during the IEP conference.

Being heard. Attempts at communicating tend to fail when one party does not feel heard. Pruitt, Wandry, and Hollums (1998) interviewed 73 parents of children receiving special education services and found parents very concerned about the unwillingness of educators to listen to their input about their children and their family issues. Parents described the disappointing quality of communication between themselves and the professionals, and offered advice:

> The results of this study revealed a complex set of issues related to interactions between parents and special education professionals within the school setting. The following common themes emerged in the data: (a) Listen to us, (b) develop effective communication between parents and professionals, (c) increase knowledge about various disabilities, (d) demonstrate sensitivity, (e) demonstrate respect for my child and meet his or her individual needs, and (f) improve the IEP process. Furthermore, in the listen to us category the overwhelming majority of the parents (70% of the respondents) recommended that educators should realize that parents know and understand their children; their contributions and suggestions are valuable and should be heard and respected. (Pruitt, et al., 1998, p. 3)

Findings from this study are consistent with those of Salas (2004) and Jones and Gansle (2010) who concluded from studying Mexican American parents of children with special needs that their input was frequently not respected during IEP meetings.

Garriott, et al. (2000) argued prior research in the area of parental involvement and participation in the IEP planning process provided an overall distressing commentary on the state of affairs in parent/professional relationships. The results of their study indicated 89 percent of participants always attended the IEP conference of their children, but half of these individuals automatically assumed a passive stance within the partnership, and 26 percent of parents questioned were not satisfied with their level of involvement. "These parents indicated that they attended IEP conferences to be informed about the educators' plans for the child or young adult

rather than to be equal participants in the development of the plan" (Garriott et al., 2000, p. 42). The desire to be in attendance at the IEP conference reflects the determination of parents to actively participate in their child's education.

Cultural influences. Parent-teacher partnerships are important for all students from preschool through high school, but a cohesive home-school relationship is especially critical for students who have special needs. Students with learning disabilities require ongoing communication between home and school (Spinelli, 1999). Keith et al. (1999) found children performed better academically and socially when their parents were involved with educators. These effects function independently of family socioeconomic background variables.

Figuring out how to engage parents from ethnic and linguistic backgrounds different from the school personnel's cultural background may challenge educators. Immigrant families come with educational expectations for their children but lack a familiarity with the U.S. education structure (Al-Hassan & Gardner, 2002). "In some cultures, parents may see involvement as interfering with the school—that they are merely consumers of services. Moreover, they may typically have been passive participants in the educational process in their native country" (Al-Hassan & Gardner, 2002, p. 57).

Unfortunately, despite the 25 years of government mandates, special education programs in the United States still lack active involvement and participation from parents of diverse cultural and linguistic backgrounds (Thorp, 1997). Yet, involving parents and families becomes a difficult issue in improving the academic and social development of students with disabilities, especially when the parents come from an ethnic and linguistic background different from the teacher (Sileo, et al., 1996).

Harry, et al. (1995) completed a longitudinal, three-year study investigating the participation of African American parents of 24 preschoolers in special education. "The findings of the study pointed to three themes: "expectations to disillusionment," "participation and advocacy," and "deterrents to advocacy""(p. 369). They explained the themes in the following passage:

> Findings under the theme expectations to disillusionment indicate that all parents of children in special education programs expressed the belief that the goal of the preschool special education class was to give the child a chance to "catch up." Over the course of three years, it became clear that parents' early notion of giving the child a chance to catch up evolved into disillusionment focusing on inappropriate placement in self-contained classes, isolation of special education programs from the mainstream, and parents' perception that the label "mental retardation" was being used for their child. (Harry, et al., 1995, p. 369)

Under the theme of participation and advocacy, parents reported the welcoming and open atmosphere of the preschool classroom diminished in the kindergarten year and was noticeably missing in the first-grade year. The findings under the theme deterrents to advocacy revealed five aspects of professional behavior functioning as deterrents to parents' participation and advocacy:

1. Late notices and inflexible scheduling of conferences.
2. Limited time for conferences.
3. Emphasis on documents rather than participation. When parents were asked how they perceived their role in the conference, the majority consistently replied that their main role was to receive information about their child's progress and to sign the documents. (Harry et al., 1995, p. 9)

Summary and Gaps and Tensions in the Literature

Since the reenactment of IDEA in 2004 and for the past 30 years much has been written about parental experiences at the IEP conference. I located studies related to parental experiences at the IEP conference, the importance of communication and participation between

parents and school professionals, barriers to communication, and parental perceptions of the IEP conference.

There is a gap in literature regarding the nature of communication between parents and school personnel during the IEP conference. Most of the current literature centered on relatively positive feelings by parents toward the IEP conference, while earlier literature contended parents largely felt unsatisfied with their participation. Parents did not appear to be equal participants and reported dissatisfaction with their experiences during the IEP conference (Engel, 1993; Gilliam & Goleman, 1981; Goldstein et al., 1980; Martin et al. 2004; Poland et al., 1982; Sonnerschein, 1981; Sonnernschein, 1981; Turbull & Turnbull, 1990; Winters, 1993; Pruitt et al., 1998). From the relevant research available, Fish (2006) and Gordon and Miller (2003) suggested parents believed their experiences were relatively positive. Fish (2006) suggested the need for further research in this area and noted that parents' assessments of special education programs were not based on any clear objective data.

Several theories proved useful in forming my conceptual framework and analyzing my findings. These included the grief and loss model of Lamb (1998), and Kübler-Ross and Kessler (2005); structural role theory (Turner, 2002); and chronic sorrow (Olshansky, 1962). I describe each of these theories next, providing a description of the theory and its application to my review findings.

Analytical Literature

Analytical theory provided a lens through which to view the study's findings and to identify emerging patterns and themes (Maxwell, 2005). Maxwell (2005) explained, "A useful theory illuminates what you see" (p.43). I adopted structural role theory (Turner, 2002); the grief and loss model of Lamb (1998), and Kübler-Ross and Kessler (2005); and chronic sorrow

(Olshansky, 1962) to analyze my findings**.** I adopted structural role theory as a lens to examine parental engagement in the IEP conference.

Role Theory

Origins. The idea of role, as a part one plays, has been recognized for centuries, but study specializing in role did not develop until the 1930s (Biddle & Thomas, 1966). Precursors to role theory included studies of labor division, complying with rules, status, social forces, interaction, and various theories of self (Biddle & Thomas, 1966). The origins of role, as discussed in role theory, actually came from the scripts memorized by stage actors (Biddle & Thomas, 1966). Using the stage analogy, Biddle and Thomas (1966) explained role theory as it applied to real life:

> Individuals in a society occupy positions, and their role performances in these positions are determined by social norms, demands, and rules; by the role performances of others in their respective positions; by those who observe and react to the performance; and by the individual's particular capabilities and personality. (Biddle & Thomas, 1966, p. 4)

The meaning of any given role is interdependent with other roles in a system: therefore they are complimentary (Bess & Dee, 2008).

Role Theory is designed to help explain how individuals in specific social positions are expected to act and how they expect others to act (Hindin, 2007). Rather than existing as a single theory, role theory is actually a term used to describe a set of related theories all seeking to explain how social behavior is organized and given meaning for individuals and groups in terms of roles (Turner, 2002). A *role* is defined as a dynamic set of recurring behaviors, both expected and enacted, within a particular group context (Zigurs & Kozar, 1994). The basic premise of role theory is that actions and sentiments tend to be differentiated into roles (Turner, 2002).

There are two versions or types of role theory according to Turner (2002): *structural* theories and *interactional* theories. Structural role theories describe the sets of expectations

placed upon individuals based upon their status in a given social structure. Individuals are thought to possess a role set which helps describe the expectations (explicit or implicit) placed upon them depending on who the other persons are in a particular interaction. Therefore, structural role theories assume roles begin with status or position in social situations and the expectations concomitant with the role are subsequently imposed upon the individual. Interactional role theories, on the other hand, assume roles represent a patterning of behavior emerging from dynamic interaction in a social context (Turner, 2002).

Structural role theory. Structural role theory provides an important lens for understanding the nature of roles in team settings. Position or status roles are linked to positions in organizations and formally organized groups (Turner, 2002). If each member of a team has a designated role (in the case of this study: teacher, principal, psychologist), then the group will place expectations on each individual to behave in ways consistent with each perceived role.

Structural role theory also serves as an important background to the understanding of formal external team leadership. When someone has formally been given the role of "team leader" or, in this study, "administrator," there is a resulting set of expectations placed upon the person and their behavior and subsequently the behavior of other members of the team.

Role theory applies to my review findings concerning the expectations parents adopt regarding their role as parents. Individuals essentially conform to the role they are expected to play. In the case of the IEP conference, each individual has a designated role; other members of the group expect each individual to behave in ways that are consistent with that designated role. The implications are that parents may take a passive role, believe school officials are the experts, or feel their input is not of equal value to school personnel. The expectations that parents assume regarding their role may be directly affecting their participation in the IEP conference.

Next, I describe grief and loss, types of grief, chronic sorrow (Olshansky, 1962), and their application to special education.

Understanding Grief and Loss

There is no conclusive definition of grief in the literature. Hooyman and Kramer (2006) "defined grief as the physical, psychological, and social reaction to the loss of something or someone important to us" (p. 16). "Grief is complicated, unique for every individual, confusing and confounding" (Hanson, Carpenter, & Fairchild, 1993, p. 65). Disability-related grief is different from bereavement-related grief in that with disability-related grief, parents have difficulty understanding what is lost (Kandall & Marrick, 2003). The loss felt by parents is for the child they had envisioned having, for what they had hoped their child might become, and for the role they envisioned having as parents (Featherstone, 1980; Hilton, 1993; Kandall & Marrick, 2003). Parents may feel guilty for grieving because they have not physically lost their child, and yet they still experience these emotions of grief (Kearney & Griffin, 2001). Foley (2006) described this loss as a "loss less total and less final than loss by death, [but] nevertheless…no less real and perhaps no less painful" (p. 231).

Parents primarily write the literature associated with having a child with a disability and grief. Ann Bouchey (2001) wrote an article about her experiences when her son was diagnosed with autism. She wrote about the grief experienced when her once typically developing son was no longer reaching developmental milestones. Her son was diagnosed with autism by the end of kindergarten. She reported being in denial for quite some time, prior to experiencing intense depression, until she finally confronted her child's diagnosis. In her writing, she reported feelings of isolation, guilt, panic, anger, and determination to find a cure before she was finally able to accept that her son had autism.

Another essay written by Susanne Carter (2004) titled "For Just One Day" answers a question posed to her by a college student. The student asked if she could take away her son's disability, would she? She admitted to wondering what it would have been like if for "just one day" she could take his autism and Down syndrome away. She wrote a fictional conversation with her son, about what he would be like as a person, who he would become as an adult, and whether he would marry and have children. She described the grief she experienced as her son went through different developmental stages. At each stage she would visit one or more of the grief stages and would wonder what it would have been like to have a son without autism and Down syndrome.

Types of Grief and Loss

There are several different types of grief and loss. These models may be described using several frameworks. Traditional grief frameworks regarding death have been adapted over time to apply to disability and parental grieving.

Nonfinite loss and grief. Bruce and Schultz's (2001) book, *Nonfinite Loss and Grief*, was written for families experiencing loss due to chronic illness, disability, or accident. Bruce and Schultz are mental health practitioners who work with families experiencing similar emotions after receiving a diagnosis of a family member's illness or disability. When family members passed through the stages of grief, they continued to revisit these stages each time an environmental trigger reminded them of the loss they had experienced.

The stages of development appear to be discontinuous. As students develop or have setbacks family members often returned to stages encountered and resolved at an earlier stage (Bruce & Schultz, 2001). Bruce and Schultz (2001) found these families did not pass through the stages just once, but continually revisited different stages as they faced natural developmental

milestones not reached, or when the parents were confronted with setbacks due to the treatments or the natural progression of the illness. It was for this reason the researchers coined the term nonfinite loss and grief. Grief is continually experienced throughout the life of the family and the individual's development.

Bruce and Schultz (2001) use nonfinite to "refer to losses that are contingent on developmental, passage of time, and on a lack of synchrony with hopes, wishes, ideals, and expectations" (p. 7). The concept of nonfinite loss may be experienced as a result of working with counselors, educators, and parents of children with developmental and intellectual disabilities. As they continued to work with families throughout the course of the illness, it became apparent that they were grieving (Bruce & Schultz, 2001). The parents grieved the loss of the child they had dreamed of knowing, and also their hopes, and plans for the future (Ozgul, 2004).

Ambiguous loss. Boss (1999) defined ambiguous loss as a loss not clearly defined or recognized, or in cases where the griever is not recognized as legitimate. Boss (1999) identified two types of ambiguous loss. In the first type, the person is perceived as being "physically absent but psychologically present, because it's unclear whether they are alive" (p. 8). In the second type, "a person is perceived as physically present but psychologically absent" (p. 9).

Brody (1999) discussed the reality of her husband being psychologically absent, but physically present after suffering a stroke. She indicated this type of ambiguous loss may also be experienced by those connected to individuals who struggled with mental illnesses like schizophrenia or depression, suffered from debilitating neurological damage, were addicted to alcohol or other drugs, had autism, or who were obsessed with work (Brody, 1999). Parents who

have a child with a developmental or physical disability experience ambiguous loss because they experience the loss of the child they had expected.

This next section will examine three perspectives that have been applied to disability related grief. They include the grief and loss model of Kübler-Ross and Kessler (2005), later adapted by Haley, et al. (2013), and chronic sorrow conceived by Olshansky's (1962).

Grief and Loss Model

Definition.

In 1969, Elizabeth Kübler-Ross, a Swiss physician developed the five stages of death and dying in response to her work with terminally ill patients (Kübler-Ross, 1969). Her constant exposure to individuals who knew they were at the end stages of their life gave her opportunities to observe patterns of behavior. She theorized all human beings facing terminal illness go through five different and distinct stages before death. While the length and order of the stages had variation, the composition of the process remained fairly constant. They include denial, anger, bargaining, depression, and acceptance (Kübler-Ross, 1969).

When Elizabeth Kübler-Ross (1969) in her book *On Death and Dying* initially developed the five stages - denial, anger, bargaining, depression, and acceptance, she put them in the context of someone dealing with being diagnosed as terminally ill. Over the years, these stages were adapted and became applicable to anyone who experiencing any form of grief or loss. Some debate has occurred as to whether individuals must go through all of the stages, and if so, must they go though them in some particular order. In response, Kübler-Ross asserted these stages do not necessarily happen in order (Kübler-Ross & Kessler, 2005).

The concept of the five stages of dying has proven to be a flexible framework. After time, they were renamed the Five Stages of Grief and expanded to apply to anyone who is

grieving and then further extended to be relevant to anyone facing bad news (ChangingMinds.org, 2008). The five stages are characterized by a unique set of emotions that distinguish them from one another (Kübler-Ross & Kessler, 2005). Denial is often described as a defense mechanism, an escape from the acceptance of reality—something people use to protect themselves from harm and enable them to cope. The second stage, anger can take many forms in varying degrees. Anger, although a perfectly normal part of grieving, potentially can lead to the most destructive behaviors (Kübler-Ross & Kessler, 2005). Sarcasm, cynicism, verbal lashing, physical destruction, self-destruction, and abuse, can all represent manifestations of grieving anger.

Bargaining, Kübler-Ross' third stage of grief, may be best described as the griever trying to make "deals" with someone, power, or spiritual being that would change the outcome or situation (Kübler-Ross & Kessler, 2005). Depression, the fourth stage, is often saddled with negative connotations; however, according to Kübler-Ross, it actually represents the road to acceptance. The fifth stage, acceptance, moves the griever beyond just coming to terms with the reality of the situation toward planning for its inevitabilities (Kübler-Ross & Kessler, 2005).

Grief and loss model applied to special education. Kübler-Ross and Kessler (2005) applied stages of the grieving process to individuals dealing with the loss of a loved one. Later, Haley, et al. (2013), defined the three distinct stages of grief and loss "as the initial stage, composed of the emotions of shock, denial, and anger; the intermediate stage, of bargaining, guilt, depression, and isolation; and the final stage, composed of the emotions of acceptance and hope" (p. 238).

Haley et al. (2013) examined the initial reactions of parents whose children had been referred to special education. Parent participants represented varying degrees of educational

backgrounds ranging from less than a high school education to a master's degree. Forty seven percent of parental comments were classified in the initial stage of grief composed of shock, denial, and anger; 11 percent were classified in the intermediate stage composed of the emotions of bargaining, guilt, depression, and feelings of isolation; and 45 percent were assessed to be in the final stage of the grief cycle composed of emotions of acceptance and hope in their reaction to being notified their child had a disability or would need special education services (pp. 236-238).

Some parents are not able to achieve the final stages of the grief cycle of acceptance and hope outlined by Hammond et al. (2013). Parents who do not achieve the final stage of the grief and loss model may be experiencing chronic sorrow (Olshansky, 1962).

Chronic Sorrow

Definition. Olshansky (1962) argued some parents never reach the final stage of the grief cycle, acceptance. Rather then cycling through the time-bound, five stages of grief, described by Kübler-Ross (1969), parents continually re-experience the different stages of grief throughout the child's lifetime. Chronic sorrow, as identified by Olshansky (1962), differs from the time-bound grief in that the emotional responses to a loss reoccur for as long as the cause of the grief is still present. Olshansky noted chronic sorrow is not continuous, but there are peaks in the re-experience of the grief stages.

Roos (2009) described chronic sorrow as "a normal reaction to a living or ongoing loss of self or other due to permanent injury, disability, or illness for which there is no public recognition that legitimizes the grieving process" (p. 6). In many instances, the extent of the loss may not be fully realized for years to come, as those with chronic sorrow begin to recognize the resurgence of their grief responses throughout the life cycle (Roos, 2009). Roos (2009) further

described the phenomenon of chronic sorrow as a disparity between reality and fantasy—the existence of the loss and the dreams of what might have been or still may be.

Langridge (2002) studied the concept of chronic sorrow from the perspective of healthcare providers working with families of children with chronic illnesses, and described what parents go through as experiencing many "little deaths." They cannot grieve in the same manner as those who have lost someone to biological death, but rather they experience many disappointments, many fears. Parents have to learn to adapt to the difference between what is and what could have been, and this can be an ongoing and painful adaptation (Langridge, 2002).

Events triggering chronic sorrow. The grieving process for parents may be initiated by events like missed developmental milestones, having same aged friends, attending birthday parties, or when their child starts school. These events remind parents of their child's disability. Parents are confronted with the realization their child is different from their peers and may never experience the life they imagined for their child.

Fraley (1990) asked 79 parents to describe their emotions at the time of typical trigger events in the life of their child. These events included the discovery of additional medical problems, being surpassed developmentally by siblings or other children, exhibiting behavior problems, beginning day care, and beginning school. Using a scale prepared by the researcher, parents consistently reported feelings of shock, frustration, anger, irritability, depression, helplessness, self-pity, and self-blaming in response to such events.

In a study of chronic sorrow through personal narratives (Scornaienchi, 2003), one mother described the increase in her sorrow when she received her son's school pictures. Seeing him every day, she has a very different picture in mind. She noted school photographers always

manage to catch her son drooling or with his hair out of place, capturing and making the moment as a defining one regarding how the world perceives him.

The burdens of giving daily care to a child with a disability can also trigger chronic sorrow (Gordon, 2009). Parental exhaustion, pain in seeing the child suffer, and even financial strains can deliver much higher levels of depression and anxiety in parents of children who have disabilities as compared to parents of healthy children (Melnyk & Feinstein, 2001).

Burke (1989) performed research with 47 mothers of children with myelomeningocele, a type of spina bifida, and the results from her study revealed parental moods of grief, anger, guilt and sorrow. Burke also noted chronic sorrow was more prevalent among parents when developmental milestones were not attained by their children or if their child's medical condition worsened and care giving demands increased.

Hobdell and Deatrick (1996) performed a content analysis questionnaire with a group of 68 mothers and 64 fathers of children with neural tube defects. The findings of this study confirmed the results from earlier research by Burke (1989) regarding what they termed as triggers in mothers and fathers in their response to the child's disability. Chronic sorrow was again confirmed to be a phenomenon much different then grief and loss; it is not time bound, and it does not have a linear or time-bound resolution.

Mallow (1999) followed Hobdell and Deatrick's (1996) content analysis with another qualitative study looking specifically at the experience of 300 families living in South Dakota with developmentally delayed children. This study sampled only married couples who were members of a local support organization and had a child with mild disabilities living in the home. The final sample consisted of 19 parents, whose children had varying diagnoses including ADHD and Tourette's syndrome. Mothers and fathers differed in how they adapted to the

experience of having a child with a disability; mothers were found to report feeling chronic sorrow more than fathers did. Participants noted chronic sorrow when events or situations caused the "feeling of sadness all over again" (p. 34).

I use chronic sorrow theory to interpret my findings concerning the emotional response occurring for some parents continuously throughout their lifetime when parenting a child with a disability. Parents experiencing chronic sorrow may display increased levels of stress and sadness. Chronic sorrow helps explain an alternative emotional response of parents to the traditional grief and loss model of Kübler-Ross (1969).

Summary

I used three primary analytical theories - structural role theory (Turner, 2002), grief and loss model of Lamb (1998) and Kübler-Ross and Kessler (2005), and chronic sorrow (Olshansky, 1962) - to analyze and interpret parental experiences and engagement in the IEP conference. Additionally, I found limited research on the grieving process associated with having a child with a disability and its effects on parental participation in the IEP conference. In the next chapter I explain the qualitative research methodology I used to conduct my research.

Chapter 3: Methodology

I chose qualitative research as my method because it allowed me to closely examine parental experiences and engagement in the IEP process. According to Creswell (2013), researchers use qualitative methods for a variety of reasons and situations, including giving individuals an opportunity to share their stories, obtaining a detailed understanding of complex issues, developing theories when only partial or incomplete theories exist, or understanding contexts or settings from study participants to address a problem or issue. Researchers must be aware qualitative study requires a strong commitment to study the research question, extensive time in the field, time to analyze collected data, and time to process and prepare the final analysis (Creswell, 2013).

Qualitative research involves the studied use and collection of a variety of empirical materials—case study, personal experience, introspection, life story, interview, artifacts, and cultural contexts, along with observational, historical, interactional, and visual texts—that describe routine and problematic moments and meanings in individuals' lives (Denzin & Lincoln, 2011). This interconnectedness allows qualitative researchers to better understand a phenomenon in its natural context.

The earliest roots of qualitative research are found in the work of anthropologists and sociologists beginning as early as the 15th century, as they attempted to understand the "other" (the outsider) and culture (Morrow, 2007; Vidich & Lyman, 2000). Researchers adopted this methodology in education and other social sciences beginning in the 1960s and 1970s (Bogdan & Biklin, 2003).

Potential cases to study are abundant in educational settings. Qualitative inquiry in these settings opens a window to greater understanding of these phenomena with an in-depth richness

that otherwise may not be possible (Hays & Singh, 2012). "These approaches may help researchers and practitioners illuminate complex phenomena in their settings, specifically as they relate to the daily lived experiences of individual groups" (p. 22).

Qualitative research is inductive, flexible, and tailored to the specific situation being studied (Maxwell, 2005). The design is "emergent and flexible…[and] responsive to the changing conditions of the study in progress" (Merriam, 2009, p. 16). More specifically, in qualitative critical inquiry the goal is to "challenge, transform and empower" (p. 10).

According to Brantlinger, Jimenez, Klingner, Pugach, and Richardson (2005), "Qualitative research is a systematic approach to understanding qualities, or the essential nature, of a phenomenon within a particular context" (p. 195). Additionally, I chose a qualitative research methodology rather than a quantitative methodology because of its specific methods of data collection and recognized significance to the field of special education. Although there may be an impression that qualitative research is new to special education, its history may be traced back almost two centuries (Brantlinger, et al., 2005). "Qualitative research contributes to the fields of special education and disability studies by capturing involved people's perspectives and by adding to our understanding of discourses that shape social life in schools and society" (p. 199).

This next section explains the case study approach within the qualitative research tradition adopted for this study. I describe the research methodology used and include a discussion of the rationale for the case study approach in my research. I then continue with a description of the research design, including ethical considerations, setting, selection and recruitment of participants, data collection methods and analysis, validity, role of researcher, and

confidentiality. I summarize the major theories used to analyze the data findings at the end of this chapter.

Adopting a Case Study Approach

The qualitative case study approach facilitates exploration of a phenomenon within its context using a variety of sources (Creswell, 2013). This ensures the issue is not explored through one lens, but rather a variety of lenses, allowing for multiple facets of the phenomenon to be revealed and understood (Baxter & Jack, 2008). Yin (2009) defined the case study as "an empirical inquiry that: investigates a contemporary phenomenon in depth and within its real-life context" (p. 18). My study concerned the experiences of parents attending IEP conferences, focusing on the IEP conference as an event in one suburban school district.

The use of case study methodology is recommended when the goal of the study is to understand how or why something occurs (Merriam, 1998; Yin, 2003). A case is a specific, unique, bounded system, and the case study allows the researcher to study individual(s), events, activities, or elements of a bounded system (Creswell, 2003; 2006). Yin (2009) explained the purposes and goals of case study research: "to understand complex social phenomena... [allowing] investigators to retain the holistic and meaningful characteristics of real-life events" (p. 4).

According to Stake (2005), a case to be studied using case study tradition must be *bounded* (i.e. have distinct boundaries), be functioning or having working parts, and indicate patterned behaviors such as sequence and coherence (p. 32). Case studies are distinguished from other qualitative traditions because cases are researched in depth and the data are delineated by time period, activity, and place (Plummer, 2001). Plummer described case studies as established "collective memories and imagined communities; and they tell of the concerns of their time and

place" (2001, p. 395). The organizing principle of a case study is the case itself, and the tradition is both a process and product of inquiry (Stake, 2005).

To understand parental experiences and engagement in the IEP conference, I chose the qualitative method of case study because of its fit with my research question and goals. Using a case study approach allowed me to "explore a real-life, contemporary bounded system over time, through detailed, in-depth data collection involving multiple sources of information" (Creswell, 2013, p. 97). I interviewed parents about their experiences and engagement during the IEP conference as an event involving multiple participants at a single location.

According to Yin (2003) a case study design should be considered when: (a) the focus of the study is to answer "how" and "why" questions; (b) you cannot manipulate the behavior of those involved in the study; (c) you want to cover contextual conditions because you believe they are relevant to the phenomenon and context. My study meets Yin's criteria.

I hoped to understand how effective communication and active engagement in the IEP process might improve the collaboration between parents and school personnel. My case study included all of Yin's (2003) criteria for case study research. My study addressed the "how" and "why" questions regarding IEP conferences. I sought answers to the questions regarding why some parents appeared pleased with their level of engagement and partnership with school personnel, while others described particularly harrowing experiences at the IEP conference. I avoided manipulation of participants by listening to their "meeting history" and examining documents concerning their child's education experiences. I examined the context and factors affecting parent participation, including how certain factors influenced the communication, collaboration, satisfaction, and engagement in the IEP conference.

One advantage to the case study approach is the close collaboration between the researcher and the participant, enabling participants to tell their stories (Crabtree & Miller, 1999). Researchers tend to collect data in the field at the site where participants experience the issue or problem under study (Creswell, 2013). Being involved professionally as a special education teacher, assistant principal, and director of special services allowed me the opportunity to attend IEP conferences and meet parents of students with disabilities. This environment, with permissions granted and protections in place, gave me access to interview participants, conduct observations, and examine historical documents for my study.

In case study research, data is collected, interpreted, and used to generate themes to improve understanding of the phenomenon being studied (Merriam, 1998; Yin, 2003). For example, after a preliminary analysis of my data (described in detail later in this chapter and in my findings), I expanded my view of the IEP conference as a single event, and instead viewed the IEP conference as an experience involving three phases: (1) parent anticipation and preparation for the IEP conference, (2) the experience of attending and participating in the IEP conference, and (3) the post-conference experience and reflection of parents, and its effects on them as individuals and their ongoing relationships with school professionals providing special education services. Case study research and qualitative research in general allow for an inquiry approach, promoting a deeper understanding of the case as it progresses and the adaptations in inquiry modes and analysis. Before conducting my study, I requested permission from the Institutional Review Board.

Institutional Review Board

During the process of planning and designing a qualitative study, researchers need to consider what ethical issues might surface during the study and to plan how these issues need to

be addressed (Creswell, 2013). Researchers request a review of research plans from an Institutional Review Board (IRB) on their college campus or university campuses (Creswell, 2013). IRB committees exist on campuses because of federal regulations providing protection against human rights violations. The IRB committee requires the researcher to assess the potential risk to participants such as physical, psychological, social, economic or legal harm (Creswell, 2013). The purpose of the IRB is to protect human subjects when a researcher obtains data or identifiable private information from them.

I submitted the appropriate forms and the study application to the University of St. Thomas IRB. The IRB approved the study, agreeing that my research proposal met the ethical requirements related to the protection of participants and standards for conducting human subjects research (see Appendix A).

I then prepared consent forms, considered how to maintain confidentiality of research participants, established routines to protect the data from access by anyone but me, and considered the potential harm to participants. I established an interview protocol to inform participants of the voluntary nature of the study, and also to advise them of their rights. Having participants sign a consent form assured proper ethical procedures for the research right at the beginning of the research process. The purpose of the consent forms was to provide each participant with a brief statement of the intent of my study and an explanation of the process. I describe the IRB protections and procedures through this study as part of the methods adopted at each phase.

Setting

Suburban School District served as the source of data for the study. Suburban School District is a large, growing school district located in a metropolitan area, encompassing seven

communities. Suburban School District has a student population of approximately 18,000 students enrolled in 23 schools. Before initiating the research, I obtained permission from the IRB (see Appendix A) and the Suburban School District (Appendix B).

Selection and Recruitment of Participants

I established criteria in my selection of participants. To qualify, participants had to (1) be the biological parent(s) of a child with an IEP, (2) have a child with an IEP currently enrolled in the public school system at the kindergarten through 12th grade level, and (3) have attended at least three IEP conferences for the enrolled child. I chose this targeted population for my study because they represented people currently engaged in this process. This allowed me to learn about their recent experience regarding the nature and quality of communication and their active engagement in decision-making regarding their child's educational program in an IEP conference.

I used purposeful sampling selection to identify participants selected primarily from Suburban School District with a child receiving special education services. I contacted colleagues in the field of education via email, told them about my research, and asked if they might be interested in participating in my study (Appendix C). Additionally, I made postcards describing my research and included my contact information (Appendix D) for school psychologists within Suburban School District to distribute at IEP meetings, and to members of a Special Education Advisory Council.

Fourteen parents volunteered to participate in my study. They expressed support for the study and appeared eager to participate. Participants included 13 females and one male. Their children were enrolled in grades kindergarten to 12th grade. Parents identified their children as persons with disabilities in a variety of categories as shown in Table 1.

Table 1
Participants

Pseudonym	**Child's Pseudonym**	**Primary Disability**	**Grade**	**Yrs. Involved in Special Ed.**
Dana	Bob	Developmental Cognitive Delay	10	16
Tom	Aaron	Visual Impairment	9	11
Kris	Aaron	Visual Impairment	9	11
Erica	Eric	Deaf/Hard of Hearing	11	14
Sharon	Denise	Developmental Cognitive Delay	12	15
Jordan	Allen	Autism Spectrum Disorder	2	2
Missy	Carl	Other Health Disability	12	7
Rachel	Calvin	Autism Spectrum Disorder	7	5
Sarah	Nathan	Autism Spectrum Disorder	12	13
Jamie	Garrett	Autism Spectrum Disorder	8	10
Patti	Ryan	Specific Learning Disability	8	6
Karen	Max	Developmental Cognitive Delay	K	2
June	David Joey	Autism Spectrum Disorder Autism Spectrum Disorder	6 4	4 4
Amy	Jennifer	Specific Learning Disability	11	10

Data Collection Methods

To understand the experiences and perceptions of parents during the IEP conference, I used interviewing as the primary mode of data collection. Morgan (1998) described an interview as purposeful conversations directed by one to get information from the other. I also used historical documents and observations as supporting data collection methods.

Interviews

Creswell (2013) listed the following steps for interviewing: decide on the research questions that will be answered by interviews, identify interviewees who can best answer these questions, determine what type of interview is practical and will net the most useful information, use adequate recording procedures, and design and use an interview protocol. In the interview protocol Creswell suggested asking approximately five to seven open-ended questions, and providing ample space between questions to write responses to the interviewee's comments.

After recruiting participants, I first obtained participant permission before conducting interviews. I explained to each participant why I was conducting the research, the procedures for the interview, the risks or benefits of being in the study, confidentiality, and the voluntary nature of the study. Each participant signed a University of St. Thomas IRB consent form stating they understood the purpose of the study, their role in it, the confidentiality guidelines, and the process and options should they want to remove themselves from the study (Appendix G).

I used semi-structured interviews as a way to listen to the narratives of parents describing their experiences and perceptions before, during, and after an IEP conference. Qualitative researchers use tentative interview protocols rather than rigidly structured protocols so that questions might be modified or added to as preliminary evidence emerges (Brantlinger et al.,

2005). I designed a set of initial standard interview questions (Appendix E), but deviated from the standard questions when the opportunity arose to gain deeper understanding.

I conducted interviews from November 2, 2010 through May 5, 2014. After obtaining consent, I used a digital recorder to record each interview. I adopted a set of semi-structured interview questions (see appendix E). I started each interview with a broad open-ended question: "Tell me a little bit about your son or daughter." I used a legal pad to record my thoughts, follow-up questions, and reflections or potential themes, especially when I heard the same theme from another participant. I also recorded the interviews and used a professional to prepare an exact transcript of the interview.

Immediately after each interview, I downloaded the recordings to my personal password-protected laptop. I backed up each interview to a password-protected hard drive. I used a two-step process to produce written transcripts from interviews: (1) I secured the services of a professional transcriptionist after receiving a signed transcriber confidentiality agreement (Appendix F), and (2) I uploaded the digital recording to Verbal Ink transcriptionists and then received an electronic copy of the transcript in a password-protected email account. I next printed each transcript, placing the printed document in each participant's individual file folder along with the consent form and a printed version of my electronic interview notes in a locked cabinet. When I completed an interview, I typed my interview notes, and filed them electronically in each participant's folder.

Initial interviews ranged from 45 minutes to 110 minutes in length, averaging about 90 minutes. After I completed the initial interviews and had the opportunity to perform a preliminary review and analysis of the data, I began to see emerging themes. For example, parents described their experiences as a story, beginning with their experiences when their child

was first identified for a special education evaluation, their experiences in conferences, and their post conference reflections. Themes of shock and anger emerged when a child was referred for special education services. Parents experienced anxiety and nervousness preparing for IEP conferences. Additionally, a general pattern of behavior emerged from the data regarding how IEP conferences were conducted.

After the conference, some parents were satisfied with their participation and engagement while others were extremely dissatisfied and upset. The first round of interviews focused on what took place during the IEP conference, but did not explain the intense emotions expressed by parents. I decided to do a second round of interviews to delve more deeply into the intense emotions expressed by parents before, during, and after the IEP conference. I contacted participants and asked them to participate in a second, shorter interview.

During the first round of interviews, I told parents I may need to call them with questions raised after the first interview. All participants agreed to the second, follow-up interview. I conducted the second interviews, in-person at a mutually agreed upon location. The interviews lasted between 20 and 40 minutes during which I asked five additional questions:

1. What was your first reaction when you were told that your child was being referred for a special education assessment?
2. Do you agree with the assessment and disability? Why or why not?
3. Describe how your feelings have changed from the time of the evaluation until now.
4. Knowing what you know now, what would you change about special education law?
5. If you were at a support group for parents with children who receive special education services, what topic would you discuss?

The second round of interviews helped to clarify parental emotions and experiences during three phases of the IEP conference. In addition to interviews, I simultaneously reviewed documents pertaining to parents' perceptions and experiences at the IEP conference.

Historical Documents

In addition to interviews, I also employed the use of historical documents. These documents consisted of current and past IEP plans of participants' children, evaluation reports from health care providers or school personnel, and parents' copies of meeting minutes taken at the IEP conference. The documents allowed me to substantiate statements made by parents and probe for further information regarding how parent experiences and the services/delivery of services provided for students with disabilities within an educational setting.

Data Analysis

Qualitative research and its methodology "are characterized as inductive, emerging, and shaped by the researcher's experience in collecting and analyzing the data. During the data analysis, the researcher follows a path of analyzing the data to develop an increasingly detailed knowledge of the topic being studied" (Creswell, 2007, p. 19). Case studies take the reader into the setting with a vividness and detail not typically present in more analytic reporting formats (Marshall & Rossman, 2006).

When I received the transcribed interviews, I put them into a Microsoft Excel spreadsheet along with my interview notes. I then coded and identified repeating words, phrases, or themes.

I used seven typical analytic procedures described by Marshall and Rossman (2006):

1. Organizing the data.
2. Immersion in the data.
3. Identifying salient themes and general categories.
4. Coding the data.
5. Writing analytic memos.
6. Offering interpretations.
7. Searching for alternative understandings (pp. 156-157).

I imported the data into an Excel spreadsheet and used a different color font for each participant. To immerse myself in the data, I read and reread the data, focusing on quotes from participants. I added a column of themes in Microsoft Excel to identify salient themes and generate categories. I then began coding the data by assigning words or phrases to participant responses. Next, I wrote analytic memos consisting of notes, reflective memos, thoughts, or insights I gleaned from my analysis. I began to interpret the developing categories and themes, and finally, I searched for alternative understandings by challenging the patterns and my understandings of the data. I chose the methodological traditions described by Marshall and Rossman (2006) because this method of data analysis suits case study research well. This allowed me to "tell the story" of parents' experiences and engagement in the IEP conference.

I collected data from interviews, observation, and historical documents and then compared data until I identified viable categories for the findings by reaching a saturation point, where I had sufficient repetitive data (Marshall & Rossman, 2006). The constant comparative method allowed me to identify when participants conveyed the same perspectives of their experiences, thus reaching saturation (Marshall & Rossman, 2006).

My discovery of the stages of grief and loss allowed me to organize my findings chronologically, describing three distinct phases involved in understanding the IEP conference experiences of parents. I then analyzed these finding using grief and loss model, conceptualized by Lamb (1988), and expanded by Kübler-Ross and Kessler (2005). This model served as a foundation in examining parental experiences and engagement in the IEP conference. I also used structural role theory (Turner, 2002) in analyzing the pattern of behavior and parental roles experienced during the IEP conference. Finally, some parents never reached the final stage of the grief and loss model. For those parents I used a different analytic theory chronic sorrow (Olshansky, 1962) to analyze the themes.

Validity and Evaluative Criteria for Qualitative Studies

According to Bogdan and Biklen (2003), "Qualitative researchers try to acknowledge and take into account their own biases as a method of dealing with them" (p. 34). I was forthright with my experiences as both a special education teacher and administrator and acknowledged those lenses to participants as well as when writing this study.

Creswell (2013) focused on eight validity strategies currently used by qualitative researchers. These strategies include: triangulating data; checking findings with participants; using rich, thick description to convey findings; clarifying the bias of the researcher; presenting negative or discrepant information that runs counter to themes; spending prolonged time in the field; using peer debriefing to enhance the accuracy of the account; and using an external auditor to review the entire study. The use of multiple data sources allowed me to triangulate the data and strengthen my findings. For example, I compared interview information with the IEP documents or meeting minutes provided by parents. In addition, I asked similar questions of each participant and aimed for rich, thick descriptions of participant experiences. I analyzed the

individual transcripts and files and also compared accounts to confirm themes initially coded to ensure my research story represented the experience common to participants.

Furthermore, I used a peer debriefer to enhance the accuracy of the account. A colleague, who recently earned a doctorate and is also a researcher, reviewed and asked questions about my study. This review enhanced the study by challenging my assumptions and proposing alternative interpretations. Lastly, I used member checking to determine the accuracy of the finding by summarizing to the participants what they told me, asking for clarification and follow-up questions, and probing for a deeper understanding with a second round of interviews.

I recognize that transferability or generalization remains problematic with qualitative studies (Marshall & Rossman, 2006; Maxwell, 2005). Caution must be exercised not to generalize the experiences, perceptions, and emotions of the parents in this study to the larger population of parents of children participating in IEP conferences.

Role of the Researcher

Over the period of data collection and analysis, I have been involved professionally with attending IEP conferences and working with parents of students with disabilities. I have served in the field of special education for 13 years as a special education teacher and director of special services. This allowed me to bring my knowledge and experience to interpreting the data. This is an advantage to the interpretation of the data, but as a result, I also have biases as to how IEP conferences should be conducted and how parents should be included in the conference.

I attempted to be conscious of my biases by attending IEP conferences as a nonparticipant observer. I attended, and noted observational data during eleven IEP conferences from September 2011 through December 2012. The observational data provided details of the natural setting of IEP conferences. I took notes during my observation of IEP conferences, and

also wrote memos to a file, collecting data about interactions between parents and school personnel, including verbal and non-verbal "conversation" and emotions. These intentional observations allowed me to observe and experience typical IEP conferences without being affected by my role as assistant principal.

My biases include my perspectives as an educator in IEP conferences, where I occasionally thought parental requests were unreasonable. Additionally, throughout data collection, I began to empathize with how parents experience the IEP conference. I attempted to guard against bias in the study by identifying my authentic thoughts and feelings, employing nonparticipant observations, and enlisting the assistance of peer briefers and my advisor. This challenged me to consider alternative interpretations and use triangulation of the data from multiple sources to confirm my initial responses to the data.

Protecting Confidentiality

The records of this study remain confidential. I did not include information in any published reports that might identify participants. I protected anonymity by using pseudonyms for participants and their children in the final publication. I also used a pseudonym for the school district where I conducted my research. I downloaded and stored the recordings to my personal password-protected laptop. I backed up each interview to a password-protected hard drive located in my home office. I locked all hard copies of documents, along with the recording device containing audio from the interviews, in a file cabinet in my home office. Transcripts from the recording and other study documents (consent forms, memos, interview notes) remain secure, having been viewed only by me, the transcriptionist, and Dr. Sarah Noonan, my dissertation chair.

I plan to delete and destroy all audio recordings, transcribed data, interview notes, consent forms, and any other confidential data on November 8, 2015. I plan to shred all transcribed data, interview notes, and any other documents after my successful defense of the dissertation.

Summary

I completed a qualitative research study and adopted a case study approach to address my primary research question regarding parental experiences and their engagement in the IEP conference. The University of St. Thomas Institutional Review Board approved my study. I followed carefully prescribed procedures outlined by the IRB, ensuring the protection of participants in human subjects research. I recruited and interviewed 14 parents of children receiving special education services. Data collection included interviews, observation, and historical documents. My analysis involved immersing myself in the data and organizing it, identifying themes, coding the data, and interpreting themes. I paid particular attention to ensuring validity by using the strategies of triangulation; rich, thick description; peer debriefing, and participant checking.

In the next chapter I begin with a presentation of my findings concerning the circumstances shaping parent preparation for the IEP. This description includes when and how parents discovered their child was identified with a disability.

Chapter 4: Discovering Your Child Has A Disability

I examined the experiences of parents attending individual educational plan (IEP) conferences to understand how these experiences affected their ability to participate and make decisions regarding their child's educational goals and related plans. The information gleaned from this study is essential: Nearly one in five people have a disability in the United States, and the prevalence of disability for school-aged children in Minnesota is 12.5% (U.S. Census, 2012). Because effective communication and active engagement in the IEP process may improve the collaboration and advocacy needed to serve special education students, I hoped to learn what factors influence parental participation and to identify what strategies for fostering genuine partnerships between parents and school personnel can be fostered to make educational planning decisions for students with disabilities. I organized my findings regarding parental experiences during the IEP conferences into three stages: the initial stage, in which I examine the initial referral for special education services and parental feelings accompanying that; the intermediate stage, in which the parents begin to understand a disability may be present and they participate in the IEP conference; and the final stage of the IEP process, in which I discern parental impressions after the IEP conference and their expectations for their child's future.

Identification and Referral: Initial Stage

In this chapter, I describe 14 parents' experiences when their child has been referred for special education services, distinguishing between two contrasting pathways: a medical diagnosis and subsequent educational determination, and an exclusive educational determination.

When parents, educators, or support providers have concerns that a child is not following typical development or progressing in school, they turn to either educators or medical professionals for assistance. This typically leads to a referral for special education services by

way of two routes, either an educational determination of eligibility for special education services or a medical diagnosis and subsequent educational determination. An educational determination for special education services is based on the impact of the condition on the student's learning, while a medical diagnosis uses instruments such as the Diagnostic and Statistical Manual of Mental Disorders (DSM) to meet medical criteria.

Once a doctor or an educator recommends a child be considered for special education services, parental reactions can become complicated. Having a child with a disability is not what parents expect, and they may experience additional stressors than those parents who have a child without a disability. Parents of a child with a disability come to the school system with unique experiences; some may have detected their child has a problem but did not have a medical diagnosis. It is imperative to examine the special education process from the perspective of a parent who is trying to navigate this process and do what is best for the ultimate success of the child. Parents experience a wide array of emotions as they become involved with the IEP process.

Parents who receive a medical diagnosis for special education services may experience the initial stages of identification differently than those parents whose child has an educational determination of eligibility. In this section, I first describe parents' experiences and reactions when their child has a medical diagnosis leading to eligibility for special education services, then I describe parents' experiences when there is an educational determination of eligibility for special education services.

Medical Diagnosis

Karen, a mother of two, is in her early 40s and has a background as a special educator. Her daughter is in high school and is in the honors program at school and a gifted athlete. Her

son, Max, is in kindergarten and is receiving special education services under the autism classification. Karen referred her own child for a special education evaluation because she could see there were some needs. She stated, "I just picked up the phone and called the early childhood center and said I wanted an evaluation on my child. I could actually see he wasn't meeting some of the developmental checklists the doctor gave me."

Karen reported it was hard for her at times because she knew a little bit more than most parents because of her special education background. She said, "I also had a day care provider that's an occupational therapist, and so she could see things, so she was always pointing that out. So I felt like from the time he was born, I kept hearing what was wrong with him." Karen's day care provider continued to bring up Max's development and began talking about it with some of Karen's family and friends making the situation particularly difficult for Karen.

> So, it was kind of hard for me because I kept hearing it from other people for a while. I finally sat her down and said that if she had concerns she had to bring them directly to me. I'm very aware of the concerns. I just really wasn't ready to deal with them yet. And I wasn't.

Karen described her experiences when medical professionals were involved with a diagnosis. When Max was about six months, she took him to the eye doctor because he had strabismus. The doctor asked if Max had had an MRI to check for brain damage because there was a chance Max might have cerebral palsy. The doctor was also concerned about hydrocephalia. Karen broke down and cried because, "I was not ready to hear that…it was just a regular exam to me."

Dana has a 16-year-old junior at Valley High School diagnosed with Down syndrome. She explained she knew his condition within five minutes of his birth. When he was born the doctors were reasonably confident of that diagnosis "because his heart was so bad…and they

could tell the physical signs. Obviously, they had to do the blood testing to confirm, but they knew within five minutes that he had Down's syndrome." She continued, "So, obviously when you get a diagnosis like that, it's a lot. It just happens so quickly and you have no time to prepare for it. I just remember this bombshell being dropped with no time to prepare." Because Dana knew early on her child had the diagnosis, she has been involved with the school system since he was born. During her child's early life (from birth to the age of three), he had occupational, physical, and in-home speech therapy. He then started at the school when he was three.

Missy shared that medical professionals diagnosed her son, but the diagnosis emerged over time. She explained in order to fit under the umbrella containing his diagnosis, a child has to have conditions that fit certain timelines: a tic disorder for six months, chronic ADHD, sensory issues for a certain period of time, and OCD for a year. She claimed the process for a school evaluation took years and years, but she trusted the process. "After the initial evaluation, in the fifth grade, the team wanted him under the EBD (Emotional/behavioral disorder) classification. I challenged that and fought for him to be serviced under the OHD (Other health disabilities) category because of his medical diagnosis."

Medical professionals identified Erica's son, Eric, as having a hearing loss when he was four months old. "They didn't have newborn screenings then like they do now." Erica continued, "But we caught it pretty early, so we've known about his hearing loss forever. He has been on an IEP since he was six months old." Erica shared that it was a heartbreaking diagnosis because they did not know how they were going to communicate with their child or what his future held. "Neither my husband or I knew anything about hearing loss or anyone with a hearing loss." Erica claimed that after her initial shock, her experiences early on with the teacher

of the Deaf and hard of hearing were positive. "She was hard of hearing herself, and that was a nice connection because she was very knowledgeable about deafness and everything in the area."

Missy and Erica, who have children displaying significant behaviors, both worried about peoples' perceptions. Missy felt ashamed of her child's special needs because his behaviors in class were embarrassing and had been going on for years, while Erica wondered in regards to her son's behavioral concerns, "Oh, is that a reflection of something that we've done or on our parenting?"

Tom has a son with a visual impairment who has had two eye surgeries. He conveyed the grief he felt and stated, "Okay, we know our kid has problems but help us out here." He continued, "We quickly learned [that] because he hadn't integrated into the system [of] much of the public school— outside of preschool— we didn't have any picture of how hard is stuff gonna be for Aaron?" Tom said from there they went to the neuropsychologist and after that the "special education kind of kicked in—in high gear— and I think that's more when we had like our first IEP meeting." Tom's wife Kris added that with the son being a twin, they were privy to additional insights. "We discovered…a couple of things. His verbal skills were lagging behind his twin. And so, that was the first thing we noticed. And then at that time, Aaron developed amblyopia, where the one eye was kind of crossing in." She indicated by the time Aaron was in preschool here in Minnesota he was going to the district service center. "He started off with home visits, some occupational therapy, and then he was integrated into kindergarten… he had an IEP."

Rachel has a seventeen-year-old son diagnosed with autism. She identified that she is originally from Belgium and came to the United States 19 years ago and married an American man. Calvin her firstborn child was the kind of baby that arched when she would hold him.

From a very early age she knew something was going on but said, “Doctors don’t listen to mothers.”

Rachel was still working at the time, so when she started leaving Calvin at day care, she began getting phone calls of issues like hitting and biting. Afterwards, she realized he was probably experiencing and responding to sensory issues. She said they went through quite a few day cares, because Calvin would be removed due to “three strikes and you’re out” policies. She continued,

> [Belgium is] a very different culture. And then, having a child with a disability was very difficult to take, probably because of my upbringing. So, I think it took me a long time to accept that he had special needs, and for the longest time I would not accept the diagnosis of autism. There was nothing wrong with him. I was one of those moms that stuck her head in the sand. I know the first time I heard the word *autism* said in my presence regarding my son, and that just threw me, and I suffered greatly at that time.

When Sharon’s daughter, Denise, was born, there was no indication of any issues, but Sharon noticed her developmental delay, and it concerned her. Sharon described Denise’s numerous ear infections. She shared that Denise had seven ear infections in her first eight months, and she had pneumonia at 11 months. The doctors always said Denise’s delayed development was simply because of her illnesses. Sharon recalled, “At a year I requested that some testing be done because she wasn’t walking or talking or doing anything—no crawling. And they did a chromosome test and found that she had a piece of one of her chromosomes missing.” Denise was diagnosed with an interstitial deletion of the number 10 chromosome, and Sharon faced uncertainty about how to proceed with Denise’s education.

Sharon explained that a family friend who was in the education field called a family member and said, “Let Sharon know that she can get some services at home through the school

district." Sharon called the school district; representatives came to the house to assess Denise and she qualified for services.

These examples constitute parental experiences when a medical diagnosis led to eligibility for special education services for a variety of disability categories, including developmental delay, behavior, vision, and autism spectrum disorder. Next, I describe parental experiences when there is an educational determination that their child meets educational criteria for a particular disability category.

Educational Determination

Patti's son was in second grade when he was referred for a special education evaluation. All year long, she had thought there had to be something wrong because it just felt like school was a complete struggle. Patti talked to a friend who encouraged her to have Ryan tested. Patti's initial reaction was one of disbelief. She said, "Really? Because that didn't ever cross my mind." Patti continued, "Looking back, I could see issues in kindergarten that he was having, but it didn't even dawn on me that he might need special education." Throughout the process, Patti went through a range of emotions. She proclaimed, "I've gone through a range of emotions from being happy he's diagnosed to being angry about how they're dealing with it to being happy again."

Jordan, the mother of Allen a second grader with autism, shared that her son's first grade teacher noticed he had some difficulties sitting still and paying attention. She noticed that he didn't interact with other children. Jordan could always tell there was something different about Allen. Whenever she took him to the playground, he had no interest in socializing with the other children, and if he did— if they forced him to—he didn't know how to interact with them. She explained he had no clue what any social interaction should be like. She clarified, "For instance,

if this kid says this and then you return it with this, and then, you know, he had no idea how that worked." Jordan agreed that they needed to look into things further, but she didn't want to face that it could be Asperger's or autism. "You know, I didn't want to face that."

When Allen was referred for a special education evaluation, Jordan broke down and cried and described her reactions.

> It was denial—wondering, you know, "How can this be? Why?" I cried. I didn't want to face it. My husband at first also didn't want to face it. So when he started the testing, I had a hard time with it 'cause I didn't want him categorized or I didn't want him to have difficulty in the future with any kind of stereotype or stigma or anything that may or may not go with it. So, I had a hard time with it.

Jaimie, whose firstborn son Garrett has Asperger syndrome, shared that he was delayed in speech. He had probably only a few words at three years old, which was unusual. While she and Garrett were attending early childhood classes, Jaimie explained, "The early childhood teachers said they thought I should have him assessed by the county. So I did. And he definitely qualified for some help."

> So, that experience…I mean, testing was definitely stressful and just the idea that something isn't quite right with your kid. But you know, when you see him interacting with others you knew—I knew—something was up even though in my heart I didn't want to. Because that's hard. It was my first kid."

She further commented, "I should say having a disability designation—that's really hard just saying that your kid is *this*, which means that maybe they're not going to be as successful. I hate the designation. They're just really hard, especially the autism/Asperger one."

June reported her younger son, David, struggled starting back in second grade; they saw he was having a lot of academic troubles. He couldn't keep up and was real down about himself. He felt like the other kids were moving ahead and that he couldn't keep up with them at all. June and her husband explained they then worked with the school to get a diagnosis, some testing

from the school, to see what was going on. They ended up taking David to an outside agency, the Anderson Center for Child Development, and had him diagnosed there. She described her experiences.

> They did three days of testing on him, and we found out he's got dyslexia and this is how you deal with it. We got really super solid answers in three days. Where testing through the school—we were really struggling the whole time.

June remained irritated that outside agencies give a specific diagnosis and a specific plan to remedy, whereas the schools only recognize a "learning disability." She lamented,

> [The school] won't deal with the diagnosis specifically. And when there's scientific evidence to say that a child should go through Orton-Gillingham training or tutoring in order to help with dyslexia, the school's not going to give you that because they don't recognize dyslexia. So we were frustrated.

June has a second child with the autism classification. As she did with her first child, she grappled with accepting he had special needs. Her pediatrician diagnosed her son with ADHD but she decided to send her child to school without medication to determine: "Are they really right about it?" She got a call the next afternoon from the teacher who asked, "Is there anything you'd like to tell us about Joey?" She then said, "Okay. I think we're dealing with something."

Amy experienced the identification of her daughter having learning issues and initial evaluation for special education in the following manner. When Jennifer was four they took her to preschool screening and found out she was legally blind in one eye. Amy was surprised to find that out but said, "She was a preemie; she was born in May but her due date was September." Amy continued, "I ended up holding her back from entering preschool for a year because we had to do about three years of eye therapy. Just finding that out, I couldn't send her to kindergarten."

Amy claimed that her daughter Jennifer experienced preschool just like all the kids do, but that she had a really hard time with reading, spelling, and math when she moved on to first grade. Her daughter's testing in first grade indicated that she needed help in both math and reading. "She has very little retention. She has just short-term retention. She can't do anything, so when they do a cumulative test over a three-month period she just will bomb, which is one reason she has really never passed." She continued, "We tried tutoring in the summer. We've done everything you can think of, but it's just her memory—and I associate that with her prematurity."

Amy said it was frightening when Jennifer was first referred for a special education evaluation because Amy did not know what an IEP was. She said when they were going to pull Jennifer out for special education testing in the first grade, she was in a reading program (Reading Counts) and she didn't pass the program. "She missed getting an IEP by three points, so that was really difficult because we could see the frustration in her," explained Amy. She stated as the school year progressed it became very evident that she had to step up and say, "Now you know what? She needs help in reading and math. You need to find this kid help…bottom line." From that point on, Jennifer has received extensive special education support.

Sarah described her experiences when Nathan was first referred for a special education as, "They noticed—the teachers there noticed he was just not interacting with the kids. He did not want to participate in the group stuff. He was distracted a lot." She continued, "He also wasn't forming sentences at the age of three. He was saying words together, but they weren't full sentences. And he wasn't necessarily able to communicate everything that was in his thoughts." It was obvious to Sarah that he would get frustrated. Nathan's teachers suggested she have someone come over to the house to observe him and see if he would qualify for some kind

of special assistance. She shared, “Nobody saw the clues that he might fall in the autism spectrum. But that’s when his IEP started—[it] was when he was with that program. He’s gotten help since he was three.”

Sarah said, “I just think parents need to realize that it's okay to have their child figure out what their needs are, what they are maybe diagnosed with, and get the assistance.” Sarah knows many kids who have never gotten help because their parents were concerned about them standing out, being considered different, or being pulled out of the classroom.

Summary

Participants described feeling a wide variety of emotions as they began their involvement in the initial stages of the IEP process. Participants identified feelings of shock, anger, and denial. These testimonies, whether the child was referred for special education services through a medical diagnosis or an educational determination, demonstrate how difficult it is for parents knowing that their child is different from other children. Of the two pathways a student is determined eligible for special education and related services, I found parents who received a medical diagnosis were more prepared to accept the educational determination of disability then those who received an education determination. Although parents who receive a medical diagnosis are more prepared to accept the educational determination, they experience considerably more grief. I next analyze parents’ reactions in the initial stage of identification when their child is referred for special education using Kübler Ross’ “Five Stages of Grief” theory.

Grief Theory: The Grief and Loss Model – Initial Stage

I used the grief and loss model of Lamb (1988), and Kübler-Ross and Kessler (2005) as the theoretical foundation to analyze participant responses in each stage: initial, intermediate, and

final. First, I describe the grief and loss model ideologies of Kübler-Ross and Kessler. Then, I use this model as a foundation to analyze parental reactions during the initial stage, their child's first referral for a special education evaluation.

Parents experience a wide array of emotions and reactions when their child has been referred for a special education evaluation. These emotions can be related to the emotions individuals experience during the grief cycle. When Elizabeth Kübler-Ross (1969) initially developed the five stages—denial, anger, bargaining, depression, and acceptance—she put them in the context of someone dealing with the diagnosis of terminal illness. Later, Kübler-Ross and Kessler (2005) applied these stages to the grieving process individuals go through when dealing with the loss of a loved one. Haley, et al. (2013) defined the three distinct stages of grief and loss "as the initial stage, composed of the emotions of shock, denial, and anger; the intermediate stage, of bargaining, guilt, depression, and isolation; and the final stage, composed of the emotions of acceptance and hope" (p. 238).

The initial stage composed of the emotions of shock, denial, and anger reflects the inability to accept a child has a disability. All 14 participants expressed sentiments of shock, denial, and anger during the initial stage; some expressed a range of emotions classified in more than one emotional category. Parents may move between stages or move into the intermediate phase, but return to the initial stage. Boushey (2001), revealed,

> It does not matter what the diagnosis is. Some people will skip parts of the cycle, some will spend different lengths of time at different points. But we all begin at the same point, and that point is our reaction to our child's diagnosis. (p. 27)

Shock

Haley, et al. (2013) contended,

> Upon hearing that one's child may have a disability, many parents initially respond with feelings of *shock*. Shock may be displayed in a variety of ways such as with an emotional outpouring, flatness of affect, indifference, confusion, bewilderment, asking copious questions, or stated feelings of "not knowing what to do." The underlying thought at this stage is "I don't understand what is happening" or "What do they mean something is wrong with my child?" (p. 238)

Ten participants expressed specific emotions of shock. Karen expressed shock when she shared that her day care provider was an occupational therapist who could see things were different about Max and was always pointing things out. She said, "So I felt like from the time he was born, I kept hearing what was wrong with him." Regarding the therapist's concerns about Max, she said, "I just really wasn't ready to deal with them yet."

Dana, Tom, and Kris shared similar sentiments. For example, when Dana's son was born with Down syndrome she had no time to prepare for the diagnosis. She expressed her shock, "I just remember this bombshell being dropped with no time to prepare." Tom, whose son has a visual impairment and needed two eye surgeries, conveyed his shock and anger when he stated, "Okay, we know our kid has problems but help us out here." His wife, Kris, shared her confusion when she indicated that she thought Aaron was lagging behind his twin and had developed amblyopia.

Rachel expressed shock when she made the statement, "The first time I heard the word 'autism' said in my presence regarding my son, and that just threw me, and I suffered greatly at that time." Sharon did not know what to do when her daughter Denise was not crawling or talking and was later diagnosed with interstitial deletion of the number 10 chromosome. Erica was at a loss when her son was born with severe hearing loss; she had a lot of questions. She

expressed her shock and said it was a heartbreaking diagnosis because they did not know how they were going to communicate with their child and what his future held.

Sarah and Amy both expressed emotions that can be categorized as shock. Sarah shared, "Nobody saw the clues that he might fall in the autism spectrum." Amy said it was frightening when her daughter, Jennifer, was first referred for a special education evaluation because she did not know what an IEP was. Lastly, when Patti's friend encouraged her to have Ryan tested her initial reaction was one of disbelief. She said, "Really? Because that didn't even cross my mind."

Denial

Regarding the emotion of *denial*, parents may not believe their child has a disability, or may not believe the disability is permanent. During this stage of denial, parents might frantically search for proof their child's diagnosis is incorrect. Parents may search for alternative explanations for their child's symptoms or behaviors, including blaming the school or diagnosing agency for not understanding the unique needs of their child (Haley et al., 2013).

Five participants of this study experienced emotions of denial. Missy expressed her anger and denial when she described the process for a school evaluation taking years. She then challenged the EBD designation and fought for her son to be serviced under the OHD category because of his medical diagnosis. Tom, whose son also had a medical diagnosis, expressed denial when he shared they did not have any sense of how hard things were going to be for him.

Jordan agreed they needed to look into things further regarding her son but concluded, "It was denial—wondering, you know, 'How can this be? Why?'" She recalled that she cried and did not want to face it. Jaimie shared similar reactions, "Testing was definitely stressful and just the idea that something isn't quite right with your kid."

Finally, Patti felt a whole range of emotions, including denial, when she proclaimed, "I've gone through a range of emotions from being happy he's diagnosed to being angry about how they're dealing with it to being happy again."

Anger

During this stage, parents may express anger toward a variety of people (e.g., the disabled child, the school system, the diagnostician, a teacher, or the other parents). Parents at this stage may feel that life is not fair and that their family did not deserve this disability; they may also question their faith in a higher power (Haley et al., 2013).

Six participants' reactions can be categorized as anger. Missy and Erica expressed reactions consistent with anger and embarrassment at their child. Missy felt ashamed of her son's special needs because his behaviors were so embarrassing in class. While Erica thought about her son's behavioral concerns and expressed, "Oh, is this a reflection or something that we've done or on our parenting?" Rachel expressed anger at the doctors when she complained, "Doctors don't listen to mothers."

Jaimie and June both directed their anger towards the school and the diagnostician at the school. Jaimie commented it was really hard just saying that her kid had a disability. She hates the designation, "especially the autism one." June remained irritated that outside agencies give specific diagnosis and a specific plan to remedy, whereas the school just recognizes a "learning disability."

The grief and loss model ideologies of Kübler-Ross (1969), Lamb (1988), and Kübler-Ross and Kessler (2005) address parental reactions and emotions when their child is referred for a special education evaluation (*Figure 1*). Although all participants experienced at least one of the emotions of shock, denial, or anger in the initial stage of identification, I found more denial

and anger directed at the school for those with an educational determination. This may indicate that parents who receive a medical diagnosis for their child are more prepared for the educational determination of eligibility for special education. This preparedness may be an indicator of positive or negative parental communication, engagement, and collaboration as parents prepare to participate in the IEP conference.

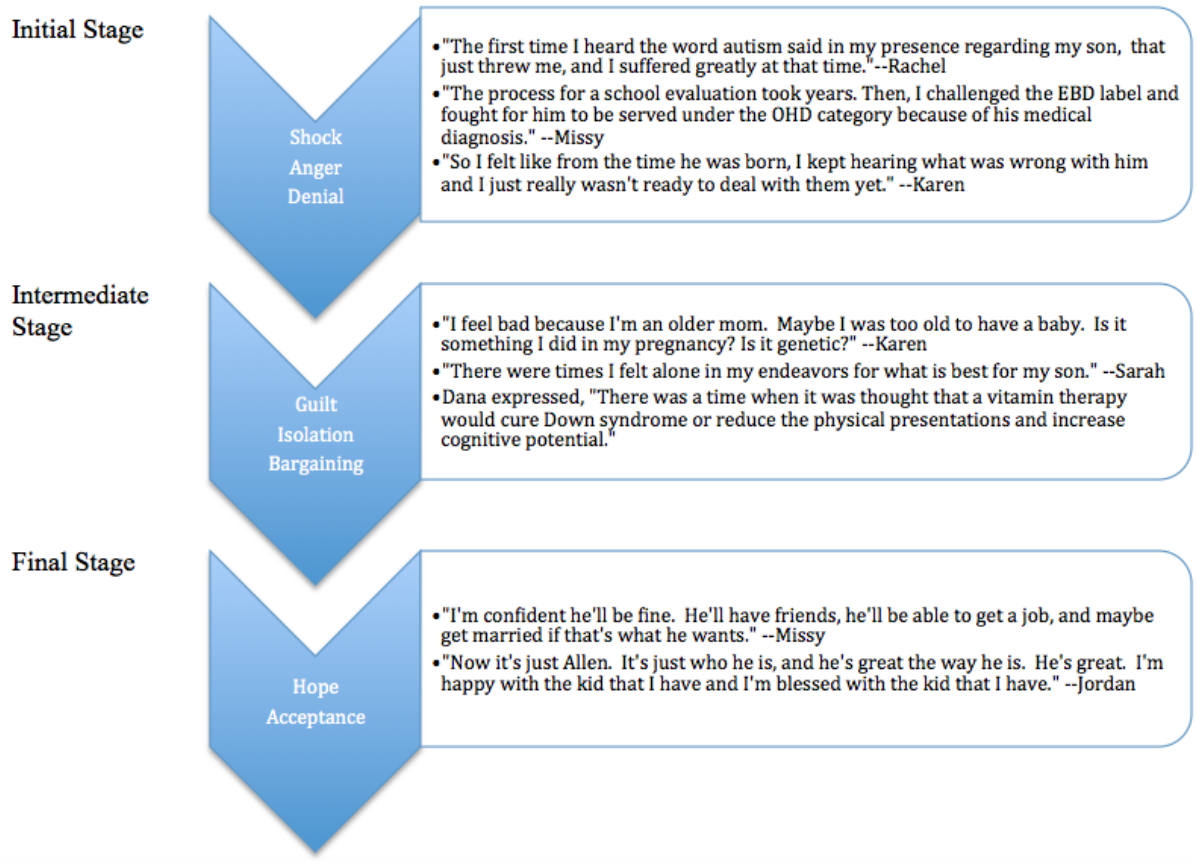

Figure 1.
Parental Grief Reactions in the Grief and Loss Model

Chapter 5: Understanding the Disability and Participation in the IEP Conference: Intermediate Stage

During the intermediate stage, parents understand their child has a diagnosis or meets criteria for special education services, yet they may not fully understand the IEP process. In addition to the feelings of shock, anger, and denial, parents may also feel guilt, shame, and isolation as they prepare to meet with school personnel. In this stage, parents are actively exploring the IEP process and its ramifications for their child. This stage includes preparing for and attending the IEP conference.

Parental Feelings

I first describe parental feelings of guilt, shame, and isolation, as well as their efforts to come to terms with these emotions. Then, I describe parental feelings of anxiousness and nervousness prior to attending an IEP meeting. Next, I identify parents' experiences during the IEP conference, including the entrance into the conference, introductions, and the seating arrangement. These arrangements elicit an "us versus them" mentality and consideration regarding who is in charge. Finally, I provide a description of the emotions felt by parents during the IEP conferences, the satisfaction with positive comments made by school personnel, and the need for personal contact.

Guilt, Shame, and Isolation

During the intermediate stage, parents often experience feelings of guilt, shame, and isolation. Some may feel like they have done something wrong or that others cannot understand what they are experiencing. During this stage, parents may also question the diagnosis or special education classification.

Three participants felt isolated during the IEP process. Karen felt isolated when attending meetings and medical appointments with her husband.

> It was hard for me because there were times where my husband would expect me to say things, and I didn't want to be that professional. I wanted to be the mom and not the professional. I didn't want to be the one consulting because I'm not a doctor and I'm not an expert. I kept really relying heavily on my pediatrician to refer me or to do things, and I found myself… I had to keep advocating and asking.

Karen also works in the field of special education with students who have moderate to severe disabilities. She thinks it's hard for her working in a special education program, knowing that someday her son could be in a program like hers. She continued, "It's hard. His birthday is coming up and he has no friends at school to invite because he's in a classroom of one. So I use my humor to mask it and I laugh about it." Karen not only felt isolation at times, she also felt guilt.

> I feel bad because I'm an older mom, and so I know some of that burden might fall on his sister when she's older. So then you have moments where you feel guilty. And then I feel like maybe I could do things differently, and maybe I was too old to have a baby. Is it something I did in my pregnancy? Is it a genetic issue? And so, I think grief comes because I question: "Could I be a better mom?"

Missy also felt guilt and spent a lot of time blaming herself. She concluded she should have known better. "I've got degrees in this. How come I didn't know what was going on?"

Sarah has had relatively positive experiences in the IEP process. "Well, I tell you. It wasn't always easy. I'm making it sound easy, but it was not always easy." There were times she felt alone in her endeavors for what was best for her son.

Sharon had similar experiences of isolation. She said because of Denise's disability, "there was no round hole to put her round peg in, I sort of had to take this on myself." She felt like she was on her own when dealing with the school system because Denise's disabilities were

so different from everyone else's. Patti described the difficulty she had in understanding the classification and evaluation process.

> They don't give you a specific name like dyslexia or dysgraphia. They say "specific learning disability." They would say things like, "Well, he is really good at spatial reasoning, but he can't get words from his head to his hand." So, that part didn't make any sense to me at the time. I just couldn't process what that exactly meant.

Jordan spoke with hesitation, "You hate to say almost ashamed, but there was a period of like, God, what are people going to think of him and how are other kids going to react to him and are they going to tease him?" She also thought,

> Where did this autism come from? You know, when I was in high school, I never heard of autism. Why is it becoming so much more…I mean, why are so many kids getting this and is it true or not?

Jaimie, Dana, Tom, and Rachel all explored the "what ifs," hoping to find a magic bullet or a cure. Jaimie said she is thankful because the IEP has helped them. She clarified,

> I should say having a classification—that's really hard just saying that your kid is *this*, which means that maybe they're not going to be successful. I hate the classification. They're just really hard, especially the autism one because I'm, like, really? Because he scored this way on a test? What if he doesn't even have autism?

Dana described feelings of hope when her son was very young and there was a time when it was thought that a vitamin therapy would cure Down syndrome, or at least reduce the physical presentations and increase cognitive potential. Tom who has a son with a visual impairment, counted on a school to fix his son, and offered, "I think every parent deep down wants a magic bullet." Rachel described her own hopes.

> My husband got me through this really terrible, black, ugly time that I went through, and then I'm this person who kinda—I'm gonna cure him. So I think I went on this journey, and we tried everything: the B-12 vitamins, we did a brain scan. We did more vitamins. We stopped short of the chelation.

These narratives presented parental feelings of isolation, guilt, and bargaining during the intermediate stage of the IEP process. I next describe parents' feelings of anxiousness and nervousness prior to attending an IEP meeting.

Anxiety and Nervousness

Of the 14 participants, 13 described feeling anxious, nervous, or worried before their scheduled IEP meeting. Two participants were relieved to have a starting point to work from. Sarah indicated she was thrilled about scheduling an IEP meeting because her son needed help, and just having the opportunity was very important for her. However, she also wondered, "What are they going to say about my child? And are they willing to give him what he needs—what I see he needs?" Karen felt anxious before attending her first meeting. She explained, "I didn't read the evaluation right away; I was too nervous." It was particularly hard for Karen because she knew a little bit and had a background in special education. She said, "It's hard to hear when they talk about your kid being low cognitively. It's hard and I don't think they can prepare you for it." Sharon, whose daughter has developmental disabilities, prepared by making a list so that she knew the topics she wanted to cover. She did not express feeling anxiety, saying instead,

> I am one that it is what it is; that I try to prepare and I go. I don't worry about it. I don't because whatever's going to happen is going to happen. It's how I bring myself to that meeting. It's what's going to be my outcome so I've got to be on my game.

The majority of participants were not comforted by the information that their child might need an IEP. Jordan, Patti, and June described feeling nervous before their first IEP meeting. Jordan, who has a second grade son with the autism classification, had a stomachache. Patti declared, "I was really nervous that first meeting because I had no clue whatsoever. I didn't even know what IEP meant." June said, "I was nervous, because we just didn't know what we

were in for. We didn't know what we could do for him through the school." Likewise, Amy shared that it was frightening because she did not even know what an IEP was.

Additionally, seven out of the 13 participants continued to feel anxious and nervous before every meeting. They admitted to crying, sleeplessness, and emotional sensitivity. Rachel cried every single time there was a meeting. Missy was always anxious the night before a meeting. Both Jaimie and June got nervous and emotional before every meeting. Erica stated,

> There's definitely a level of anxiety. And I still have it going into meetings. You have expectations for your child. And you want them to do well, and you want them to be as normal as they can be. So just going in, not knowing what you're going to hear— that's always stressful. But I always feel nervous. And I think it just goes back to just worrying about people not seeing— always seeing the best in your child. You know? And sometimes that's their job. Because they have to look at what their needs are.

Patti got nervous before every meeting because she "does not know all the rules, what all the laws are, and what they have to do versus what you want them to do. It is getting easier as my son is getting older though." Jordan had a similar experience. "I'm nervous throughout the whole thing, but I do become more comfortable. Like, I'm a nervous person, so once we get going, I start to feel a little better. But until I walk out of there I'm like, [deep inhale]. You know, you gotta let out the breath."

Summary

In summary, participants described feelings of guilt, shame, and isolation when their child was referred for a special education evaluation. Participants commonly described that the notion of having a child with a disability was a burden, that they were looking for a magic bullet, that they disliked having their child classified as having a disability, and most suggested how hard it was to know their child is different. Additionally, participants described anxiousness, nervousness, or worrisome feelings prior to scheduled IEP conferences. For some, these feelings

continued for every IEP conference thereafter. I next describe parental experiences, participation, and engagement during the IEP conference.

The IEP Conference

In this section, I identify parents' experiences during the IEP conference. I then describe emotions felt by parents during the conference, the satisfaction with comments made by school personnel, and the need for personal contact.

The Entrance

The purpose of the IEP conference is to have the team develop an educational program for the student to support progress in the general curriculum and meet other educational and functional needs resulting from the disability (Minnesota Department of Education Division of Compliance and Assistance, June 2006).

Although individual participants had unique experiences during IEP conferences, they described a generalized structure of events. Participants of the study described what they saw when entering the conference room. Five participants identified the "large" or "huge" number of people in attendance at the conference. Patti expressed discomfort.

> We walk in to everybody sitting around the table. I hate that. I like it when the case manager brings us in and then everybody kind of joins us shortly after that. It's a lot less [like] walking into a lion's den of people.

Jamie said, "You come in and there is just this huge table filled with people. It's super overwhelming." Karen agreed, "It's a big meeting to walk into. There were nine people at the table, plus my husband and myself because you had your sending team and your receiving team." Jordan described it as "preparing for a fight." Dana, on the other hand, was impressed with the number of people who attended the IEP conference. She remarked, "I mean, the

principal comes, the assistant principal, the teacher, all the therapists, the social worker. I remember feeling very impressed that so many were interested in my child and his well-being."

Introductions

Seven participants indicated the case manager started the meeting, followed by everybody going around the table introducing themselves. Erica described a meeting opening in the following manner:

> The case manager tells us this is what we're going to do today. I think sometimes they get information from us first, as far as asking what we're seeing at home, how things are going at home, and then moving into what they're seeing at school.

Other participants discussed similar discomfort. Patti felt like everyone was staring at her. Missy conveyed, "You're getting negative information about your child, and you're looking around the table trying to figure out people's perception." Jaimie described her experiences as paperwork being shuffled out. She was asked how she thought her child was doing, then the next school professional would summarize how things were going, and she was asked if they were trying to keep a goal or if they were going to make a new one. Sharon described the structure of the meetings.

> The meetings always went by who had to go to what first. So whoever had the next—another IEP, or whoever had to be in their classroom because they didn't have an aide, we would always start with that. But we usually had an IEP or all the information in front of us and we'd go through it page by page. There were many meetings that it was such an in and out that I thought, you're a check mark. You're not really a piece of the progress. There was one of the gals that she would never be there for the whole meeting. She was always a run-in-or-outer.

Sarah expressed similar sentiments.

> They typically would start with… the caseworker would direct the meeting. The caseworker would go around the room because usually the teachers needed to get going. So she lets the teachers report on what they see going on. And then…anyone who has to leave would leave, and the caseworker would go through the IEP and make notes of changes that needed to be made.

Patti said she would like the general education teachers to stay in the IEP conference longer than they do.

> Well, they always schedule it right before school starts. So, then they have to go teach a class. So, I've never been able to ask them to stay longer. It definitely limits the amount of information that they get about him. I would prefer the teacher that my son has the most problems with—not the teacher but the subject—stayed longer because that teacher needs to know the most about him.

Amy relayed her experiences at her first IEP meeting.

> I just sat there. They just kind of read through it with me and asked if there was anything that I felt that she would need. I thought, "I don't even know what services you have, so how would I know what to suggest?"

Similarly, Karen experienced her first meeting with this structure.

> The case manager, Katie, did most of the talking, and then she passed it to Amanda, the receiving teacher, who just kind of described her program and what was going on. So it's really about the school and what services he's going to get. They're there to tell you how they're going to do it. It doesn't feel like it's open for discussion.

Karen felt that school officials talked down to her like she really didn't know her child. She felt that it was "a little condescending. I can't describe the feeling, but you're assuming that parents know nothing about special education."

Participants of this study had an array of unique experiences entering the IEP conference; many described how surprised they were at the number of school personnel in the conference. They also described similar structures during the introduction stage of the conference. The next

section describes the seating arrangements and the feelings those arrangements elicited from parents.

Seating Arrangement

Parent participation may be affected by the seating arrangement. Barbour and Barbour (2001) suggested teams could use seating arrangement to establish a sense of equity among meeting participants. In this study, participants identified convergent and divergent themes regarding seating. One convergent theme was in spite of the fact that there were many possibilities where one could sit, seven participants conveyed they always sat in the same place.

I will first identify the convergent seating pattern shared by participants (see Figure 1), and then identify themes relating to seating patterns the participants shared. This included an "us versus them" mentality, their comfort level regarding the positioning of school personnel, and their perceptions of who is "in charge" or leads the meeting.

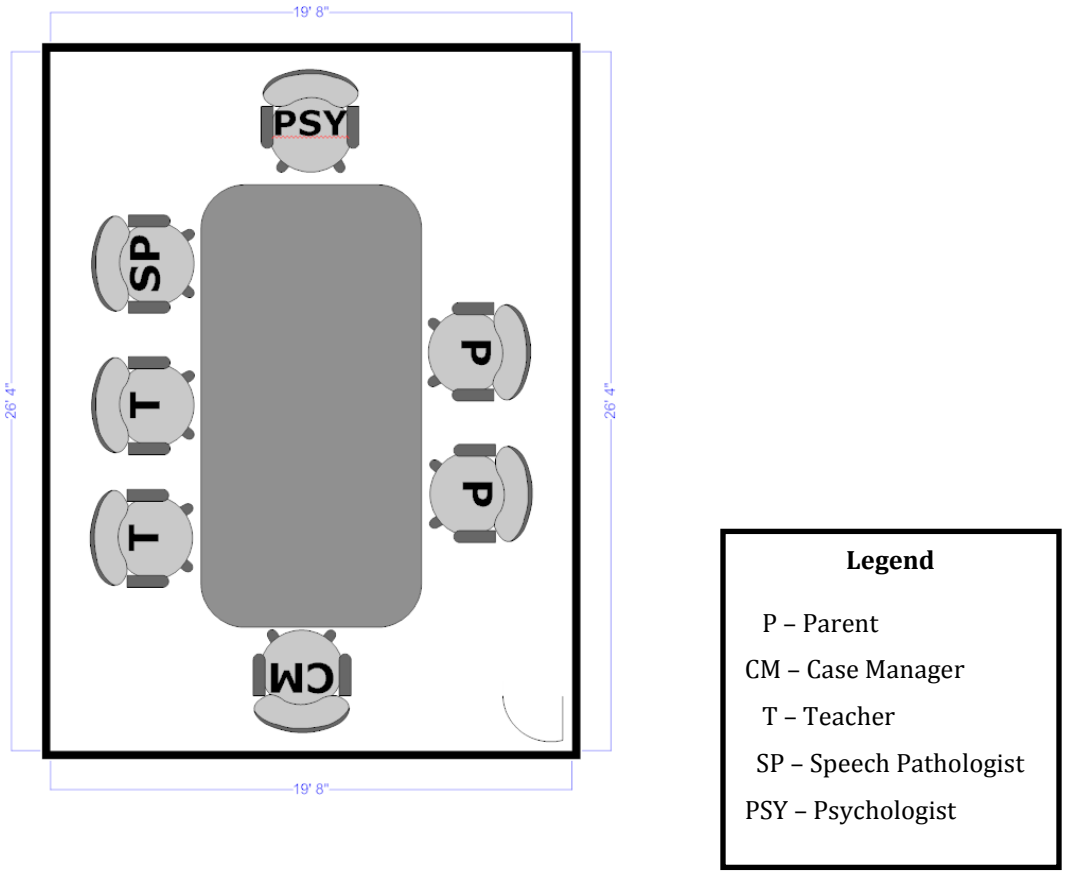

Figure 2. General Seating Arrangement

Us versus them. The seating scenario in figure 1 elicited divergent perceptions from parents. When Jamie first observed school personnel sitting around one side of the table and parents on the other, she equated it to an "us versus them" scenario. Whenever she entered this seating scenario, she found the conference stressful. Jordan shared that she felt a little stronger when her husband sat next to her, but concurred with Jaimie, stating while motioning with her arm, "it feels like 'their team' is facing 'our team.'" However, Sarah indicated that sometimes school personnel would sit next to her or across from her. "The people who were leading the IEP would sit across from me, probably to have eye contact. So usually, the caseworker would do most of the talking in that situation."

Patti and Jaimie preferred when a member of school personnel sat next to them during IEP conferences (see Figure 2). Patti conveyed, "I like when the school psychologist sits next to me…it's really calming for me."

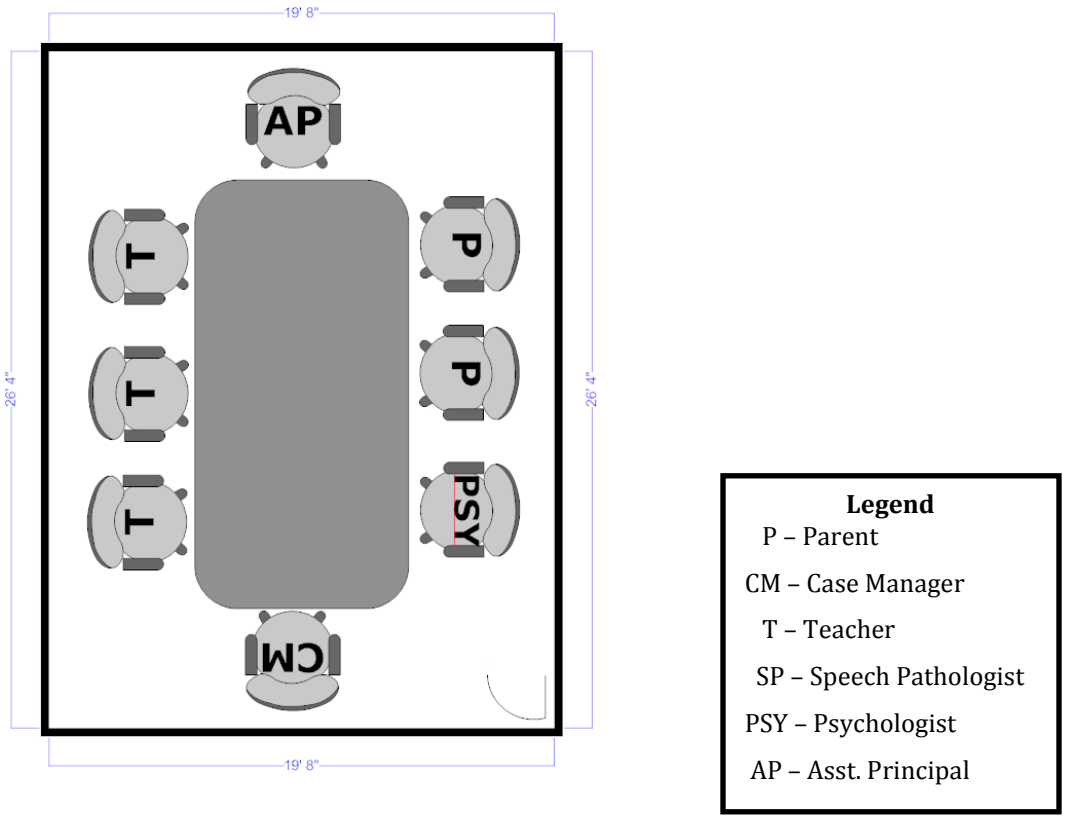

Figure 3. Divergent Seating Arrangement

June shared a particularly unique arrangement where she sat with a therapy dog. She believed that this arrangement made for the best IEP conferences for her. June explained that Nathan worked with a lady who had a therapy dog, and they knew to bring it to IEP meetings. She would take the dog, Bear, and she would pet him. She claimed, "I know that it was meant to calm the kids down, but for me, it was like, okay, I've got Bear next to me. I can do this."

Who is in charge? Participants described the meeting table as rectangular (Figures 1 and 2). This allowed for someone to sit at the head of the table. Participants perceived this head

position as the person leading the conference. Seven participants explicitly felt the case manager "runs," "leads," or "does most of the talking" during the conference. In both Figures 1 and 2, school personnel sat in this position.

Erica who has a child with an IEP and is also a special education teacher said, "I make a conscious effort when I go into a conference to not sit at the head of the table because I don't want people to think I'm in charge." She continued, "I think I would feel uncomfortable sitting at the head of the table as a parent—as I do as a teacher. I don't want to feel like I'm in that role or position." She explained at Graceland they have a due process person, and she was at the head of the table. She was the one who had all the papers and all the signatures; so, she was leading the meeting. Jaimie shared the same viewpoint when she described that Mary her child's case manager sat at the head of the table and "usually would run the meeting or kind of go through the checklist of what was happening."

Emotional IEP Conferences

Attending an IEP conference is an emotional undertaking for parents. Nine of the 14 parents reported that they cried at some point during an IEP conference. At particularly positive IEP conferences, Jaimie, Kris, and Patti cried happy tears. Although Tom did not cry, he said,

> I think just due to the nature of the way we work in this modern world, you do take a very emotional thing and you try to make— strip it of emotion to try to accomplish something. You know, parents walk into these things with all this emotional stuff, which should be there.

Jaimie recounted she cried at the first IEP conference she attended because the information she was obtaining about her son was hard to hear. She said, "I'm not a public speaker and I have to talk about my kid—which is emotional for me—in front of all these people who have opinions about his ability." Likewise, Patti does not like to cry in front of people because she is afraid

people will think she is crazy. She stops talking too when she feels like she's going to cry and "tries to end [the conference] quickly, because I need to get out of there."

Jordan cried at the first conference because "it's hard for me to know that he's pulled out of the classroom and that other students notice a difference in him because I'm afraid of him being bullied." Sharon had a different reason; she cried because she needed services for her daughter. "I said, 'Give me your name of your lawyer because I think I have to sue you in order to get services for my child.'"

Additionally, what made Karen cry at the meeting was that she had to go and get her son a little backpack, and "they wanted to put him on the bus," as she explained with a chuckle. "I didn't want to put him on the bus; he's too little for the bus. They wanted a backpack and they had a list of supplies, and I just wasn't ready to send him to school."

June, Kris, Rachel, and Missy had particularly exasperating experiences. June did not agree with the disability classification the school was using and walked out of the conference. "I walked out of that meeting in tears. I was like; this is ridiculous—that you're trying to put him in a category where he doesn't fit, to get him these services. When obviously he needs it. To us, it was very obvious." Kris cried at every IEP conference for her son but one. She remarked, "Usually, I can get out the door and make it to the curb before crying… it feels inhumane when you feel like your child is reduced to a disability on a piece of paper." Rachel remembered very little about her first IEP conference, but remembered that the school personnel were very professional, and she cried throughout the entire meeting. Missy described one particularly harrowing meeting.

> The information was so negative, coming forward—and my husband was there—that I, I just broke down and I cried. I cried so hard I couldn't stop crying, and everyone around the table was looking at me like I was crazy in my mind, right? There was a particular teacher that just kept calling me "Mom," which, by the way, is a bad thing, too. Don't refer to me as, "And Mom this" and "Mom that." So, after I cried for a while and she kept calling me "Mom," I, I lost my temper and told her that, quite frankly, I'd given birth twice in my life and that she was not a result of either one of those births. I said, "Please stop calling me Mother." 'Cause I'm not your mother. At which point, then I could make it through the rest of the meeting. I felt good. The high school rep looked at me and acknowledged the fact that it was a very negative meeting, and so I was affirmed.

Genuine, Caring, Respectful Comments

Eleven participants indicated positive experiences and satisfaction during IEP conferences when school personnel conveyed positive messages regarding their child and when they felt they genuinely cared for their child. June shared that positive feedback from teachers is very encouraging to parents. She contributed, "When all the teachers were there and they were participating, they had data, they had feedback—those were the kinds of meetings that went really good." She explained when Nathan was older, he would attend meetings— and a lot of times the feedback was really good, so he was encouraged, which was encouraging for his parents as well. Jordan had positive experiences in IEP meetings when she could see they knew what they were doing, they had her child's best interests at heart, and they wanted him to be successful. Amy had positive experiences when the school officials really knew what her daughter's strengths and weaknesses were. She explained, "They know her…they know what her strengths and weaknesses are…they've met with her teachers and know really how she is doing in their classrooms."

Specific messages regarding strengths or idiosyncrasies of the student and personalized stories have positive effects on parental participation and satisfaction during the IEP conference.

Four participants indicated successful meetings when school personnel gave positive messages about their child. Erica stated, "I could see the respect between them and Eric during the meeting. And that means a lot." Furthermore, Erica shared starting the meeting off with strengths is positive. "Not just fluffy positives, truly stuff that I can see in my son too, that they're bringing out his strengths." Missy described her experiences with school personnel during an IEP meeting, saying, "It was good because she said so many wonderful, wonderful things. She encouraged me to have faith in him because he was gonna go ahead and he was gonna be fine." Likewise, Dana shared what made her satisfied was when she felt there was a genuine caring for her child, that they weren't there to fulfill a meeting requirement. She recounted a staff member said, "We love having him as part of our school," to which she added, "As a mom that just makes you feel good." When school personnel made positive comments about her son, Patti said, "They really care about Ryan; he's such a great kid. They tell me stories about stuff that he did that was funny or that—I'm like …yeah, that's my kid." She continued with a smile, "That's the one that comes home to me every night. It's not the one that you talked about in elementary school who would sit on the floor and wouldn't leave a room because he didn't want to be around you."

Additionally, Rachel, Patti, Erica, Sharon, Dana, Karen, and Tom indicated positive experiences and satisfaction during the IEP conference when they felt school personnel genuinely cared for their child. Tom and Erica stated it made the IEP process easier. Tom saw his school personnel as "someone who you could tell cared passionately about your kid. And so, you know, that made the process just so much easier." Erica said, "When there is genuine respect and caring…then you can deal with some of those others things a little bit easier, when you know what? They cared about him. They respect him; he respects them."

Karen smiled and laughed when she described Max. "He's nonverbal right now. He's started to vocalize a little more. He's definitely a toe walker." She recalled how wonderful it made her feel when school staff told her, "When Max is really excited, his feet go a mile a minute." The teachers identified they love working with Max because he is very affectionate and smiles a lot. Karen said she feels good dropping him off every day when she hears stories like that.

Tom presented the antithesis when he described IEP meetings during the transition from middle school to high school. In middle school, Tom felt favorable when there was positive communication and school personnel knew his child. He conveyed, "Okay, I think what I'm hearing is really good and I feel like this caseworker really knows what's going on, and so we're okay." In the IEP meeting to transition to high school, however, he felt the contrary. He was dismayed at the opinion of high school personnel that "the previous IEP was not really sufficient. Then you walk out and you're like—these people don't know your kid. Okay, no one knows, really, my kid. They're not satisfied with the previous IEP."

These testimonies make evident the amount of stress and apprehension the IEP conference can generate for parents, and how positive feedback and opinions about their child can set a tone of collaboration.

Summary

The purpose of the IEP conference is to develop an educational plan for the student with a disability to be successful in the school environment. Participants described similar structures for their respective IEP conferences—attendees usually included teachers, administrators, and psychologists, as well as the case manager. The number of people in the conference surprised some of the parental participants.

Likewise, participants experienced similar structures and feelings during the introductory stage of the conference where case managers started the meeting and then went around the table to allow school personnel to introduce themselves. This stage was also characterized by a shuffling of paperwork.

Participants shared that although there were many possibilities for seating arrangements, they always sat in the same place during IEP conferences. This particular seating arrangement elicited ideas about who was actually in charge or running the meeting. Additionally, attending an IEP conference was an emotional undertaking for parents. Some came in expecting to have to fight with school personnel. Most participants reported crying at conferences, for a variety of reasons.

Finally, parents had positive experiences when school personnel conveyed positive messages about their child. These genuine comments set the tone for future collaboration. I will now further analyze these experiences using the grief theory, the grief and loss model, and role theory.

Grief Theory: The Grief and Loss Model

The middle stage of the grief model is the intermediate stage, where parents experience emotions of bargaining, guilt, depression, and isolation. Parents experienced a variety of emotions of the loss model ideologies of Kübler-Ross (1969), Lamb (1988), and Kessler (2005) while navigating the IEP process.

Bargaining

During the *bargaining* stage, parents have a "what if" and "if only" mindset. They engage in bargaining, such as: "If only we do everything right, go to church every Sunday, or try every treatment, our child will recover from his or her disability." During this stage parents are

willing to do anything if it will mean their child's disability is rescinded (Haley et al., 2013). Jaimie, Dana, Rachel, and Tom explored the "what if's" and looked for a magic bullet or cure for their children. Dana and Rachel used vitamin therapy in the hopes that it would either cure Down syndrome or reduce the physical characteristics. Tom counted on the school to fix his son, while Jaimie questioned whether or not her son even had autism.

Guilt

The next emotion that parents may experience is guilt. Haley et al. (2013) maintained that during this stage parents might ruminate on what they might have done wrong, or what they didn't do, that caused or contributed to their child's disability. Parents might have a belief that they may have been able to control or fix the disability had they just made different choices or acted in a different way (p. 239). For example, Boushey (2001), proclaimed, "This guilt was the feeling that I had done something during pregnancy or during the developmental years of my child's life that has caused his autism" (p. 29). Both Karen and Missy felt guilt about their child having a disability and wondered if they did something wrong. Karen stated, "Maybe I was too old to have a baby. Is it something I did in my pregnancy?" Missy blamed herself. "I've got degrees in this. How come I didn't know what was going on?"

Depression

During the stage of *depression*, parents are deeply discouraged. They may feel hopelessness or powerless, or experience deep sadness. Parents may question whether or not they can cope with their child's disability. They may display typical depressive symptoms including feelings of irritability, irrational guilt, changes in eating or sleeping patterns, and loss of energy or motivation (Haley et al., 2013). Karen experienced depression when reflecting on her son's disability and his impending birthday. "It's hard. His birthday is coming up and he has

no friends at school to invite." Jordan also displayed indications of depression when she contributed she felt ashamed or wondered what people were going to think of him and how others would react to his disabilities. Additionally, 13 participants experienced depression when they described feeling anxious, worried, and nervous before scheduled IEP conferences.

Isolation

During this stage, parents may feel that no one else can understand what they are going through. Parents may feel that they cannot relate to other parents who have "normal" children. There may be a loss of social contact, and family members might also withdraw from each other as each family member tries to cope individually (Haley et al., 2013). Karen, Sarah, and Sharon experienced isolation at times. Karen felt isolated when attending meetings and medical appointments with her husband because of her background in education; she wanted to be a mother, not a professional. Sarah expressed there were times that she felt alone in her efforts to do what was best for her son. Likewise, Sharon had similar experiences of isolation because her daughter Denise's disabilities were so different from everyone else's.

Summary

Parents experienced emotions of bargaining, guilt, depression, and isolation as they navigated the IEP process. Additionally, the emotional nature of the IEP conference experienced by parents may directly correlate to the grief and loss they are experiencing regarding having a child with a disability. I next utilize role theory as a lens to analyze parental experiences in the context of the IEP conference.

Role Theory

Rather than existing as a single theory, role theory is actually a term used to describe a set of related theories: these theories seek to explain how social behavior is organized and given

meaning in terms of roles played by individuals within groups (Turner, 2002). A *role* is a dynamic set of recurring behaviors, both expected and enacted, within a particular group context (Zigurs & Kozar, 1994). The basic premise of role theory is that actions and sentiments tend to be differentiated into roles (Turner, 2002).

Structural Role Theory

Structural role theory provides an important lens for understanding the nature of roles in team settings. Position or status roles are linked to positions in organizations and formally organized groups (Turner, 2002). If each member of a team has a designated role (in the case of this study: teacher, principal, parent, psychologist) then the group will place expectations on each individual to behave in ways consistent with their role. One example is, if a team member is regarded as the subject matter expert, then the team would likely place expectations on that person to weigh in strongly on issues related to their expertise. Another example would be when team members bring a formal organizational role to the team, such as principal or school psychologist, they are likely to have expectations placed on them based on their identity. Therefore, structural role theory can be used to describe how the team will place expectations on individual team members based on formal or informal roles.

Structural role theory also serves as an important background to the understanding of formal external team leadership. When someone has formally been given the role of "team leader," or in this case of the IEP conference, "administrator designee," there is a resulting set of expectations placed upon the person and his/her behavior and subsequently the behavior of other members of the team.

Structural Role Theory and Who is in Charge

Structural role theory provides an analysis for understanding the real or perceived roles of individuals in an IEP conference. School officials are seen as the experts in the field of education. Teachers, school psychologists, and administrators are highly trained professionals with expectations placed on them based on their expertise, and great weight is placed on their opinions. Structural role theory presents a contrasting dynamic of experts and laypersons. Additionally, this same theory can also be used to examine the seating arrangement during the IEP conference.

Structural Role Theory and Seating Arrangement

Participants in this study identified that they always sat in the same place. This seating arrangement placed parents sitting next to each other and school officials sitting across from them and at the head of the table. Participants perceived this head position as the person leading the conference. Analyzing this scenario utilizing structural role theory, the individual seated at the head of the table had been given formal team leadership status. Therefore, if the school official was the team leader, then parents and others were seen as subordinates. When crucial decisions or consensus needed to be achieved, the "lead" individual was the one who the team members looked to for answers.

Summary

Kübler-Ross' "Five Stages of Grief" theory and the loss model ideologies of Kübler-Ross (1969), Lamb (1988), and Kessler (2005) informed the analysis of parental experiences and reactions during the intermediate stage, understanding the disability and participating in the conference. As parents progress from the initial stage to the final stage of the grief and loss model they may move back and forth between the stages and through different emotions within

each stage. In the next chapter I describe parents' experiences and reactions in the final stage—the period after the IEP conference.

Chapter 6: Parental Impressions and Expectations: Final Stage

During the final stage, parents begin reflecting on possible interventions and current programming, and what the future holds. It is hoped during this stage, parents are able to reflect on their experiences and move forward rather than looking back.

In this section I identify parental feelings after the IEP conference. I describe parents' analysis of the conference, how they evaluated their communication with school personnel, what made them feel satisfied when leaving a meeting, and recommendations for increasing participation. Additionally, I identify parents' hopes for their child's future.

Post-Conference Impressions

After the completion of the IEP conference, participants have a variety of unique impressions. For some participants, IEP conferences bring back reminders that their child has a disability. Four participants indicated they spend from one hour up to a week or two analyzing and resolving their thoughts regarding the conference and their child. June said she and her husband would be really stressed. "Sometimes we'd have to look at the positives and things like that. I try to put it away after an hour." Jordan reported being relieved that it was over.

> I sit in the car and rethink the whole thing over and over, like, "Did I say the right things?" When I get the IEP home to sign, I read it 10 times at least…it's not that it's going to change or anything, but I just want to make sure that I don't miss anything.

Erica's mindset is the epitome of this scenario; she described an experience with her husband after a meeting.

> I get so nervous beforehand, I always think, "Oh, I should have said this. Or should we have done this differently? Or should we take it to the next level?" This last meeting I thought about it for a long time because I had to talk with friends and asked, "What would you have done? Or how would you deal with this?" During the car ride home my husband and I talked about how frustrated we were with the communication. We even forgot to stop and pick up his car in Eagan. We drove all the way home so we had to go back and pick up his car.

Of all participants, Patti took the longest time to sort out her feelings regarding the IEP conference. She reported, "I process forever, a good week or two. I think about, like, I should have asked about that, I should have said that, I shouldn't have said that." Participants process both the substance of the meeting and the communication interactions.

Factors Influencing Quality of Interactions

Participants of this study evaluated their communication interactions and level of participation with school personnel. Participants felt positively about their communication and interactions with school personnel during the IEP conference when they knew the IEP was going to be followed, when their child was meeting his or her goals, when they felt listened to or heard, and when school personnel validated their parenting skills or opinions. Five participants communicated they felt satisfied when they knew the IEP was going to be followed, and that their child was achieving his or her goals. Amy remained hopeful and claimed what made her feel satisfied when leaving an IEP conference was "that the things that are on there are going to be followed…when it says that they have this modification or can have this read to them that it's really going to happen." On the other hand, what made her feel unsatisfied with her participation in the IEP conference was when "what you know was in the IEP and should be followed isn't being followed." Erica shared similar sentiments that she felt satisfied when she left the IEP conference knowing that the IEP was going to be followed. She shared a situation regarding a recent IEP conference where she felt disappointment because service providers did not attend. "I think it was a level of frustration…knowing that we really didn't get out of the meeting what we had hoped to get out of the meeting. I felt like I had to just concede to that, without really feeling that that was what was best for my son." Patti also felt satisfied when she knew that the

IEP was going to be implemented as discussed at the conference. She said with a confident smirk, "Okay, we got all this down; this is gonna work."

Jordan had trust that school personnel were doing what was best for her child. She said, "I feel satisfied. I'm trusting that they know their job, they know what they're doing, and they know what's going to help him. I feel like I can give input, but I believe that they're steering me in the right direction." Additionally, she felt satisfied when her son was making progress. "When I see that he is making some advancement, when I see that they're changing it because he's meeting their goals, I realize he's met this goal—so now we're going to work towards something else," she proclaimed proudly.

Karen also expressed her trust in school personnel and the gains Max was making. She shared, "I just really feel like the school is doing what they can to support us. I really felt like the evaluation the school did was really thorough and had a really good picture of him." She continued, "And I feel like he's making gains. I'm really okay with what school is doing. I trust school."

Sarah and Sharon both felt satisfied, trusting that the school was doing what is best for their children. Sharon proclaimed, "I'm satisfied when I leave a meeting and I see that they have really responded to where she's at and they really know her…you definitely know who you can trust."

Feeling "heard" and providing input. Participants evaluated communication interactions with school personnel positively when they felt they were being heard and were able to provide input. When discussing standardized test scores and technical terms, Patti felt less engaged than when the team was discussing adaptation for her son.

> So if they're talking about his testing and they're using the Woodcock Johnson blah, blah, blah, whatever—I don't know what any of that means. But when they're talking about his adaptations I feel good about the conversation because I know my kid. I know what's going to set him off, what's going to alleviate his stress. I know exactly what he needs because I'm his mom.

She continued, "When I feel inferior I want to participate less. I just wanna shut up and hide in a corner." When June feels listened to, she feels satisfied with her communication. "I could say what I needed to say and get things out. Like I was being listened to—because you always want to feel like you're part of the team, not like on the other side of the table."

Affirmation and validation by school personnel. Parents reported feeling satisfied with their participation in the IEP conference when they felt school personnel listened to what they said and allowed them to feel heard. Additionally, five participants specifically stated that words of affirmation and validation from school staff made them feel positively about their communication and interaction during the conference. Patti stated, "I feel satisfied when I ask for something and they say, 'Yes, that's exactly what we want.'" She continued by saying, "That makes me feel good." Michelle explained she feels positive when school personnel affirm her requests; "I feel satisfied when I think I have a justified request, when I say that I'm not happy with something. And I think that makes me feel satisfied when I think, 'I was right to bring that up.'"

Praising parents for their commitment to their children is effective and welcome. When Jordan leaves meetings, she indicated she wants to just "get out of there." She described the idle chitchat down the hall; "They always praised us for how hard we work with our kids and stuff." This made her feel good "because I stayed home because I knew they needed extra help." Both Jaimie and June mentioned they are affirmed by positive comments regarding their parenting.

Jaimie said, “It feels good when teachers praise my parenting,” and June explained, “You want to make sure that your teachers think that you, as a parent, are doing a good job.”

Recommendations for Increasing Participation

Participants identified recommendations that may aid in increasing the level of parental engagement and participation in the conference. These included initiating personal contact, communicating with a single school contact, and being connected to other parents. Four participants indicated that having paperwork such as evaluation reports and agendas sent home prior to the conference increased their ability to participate. Erica wanted more than just a basic agenda, one with more specific concerns needing to be addressed. She experienced meetings where she was unprepared for topics raised by school personnel and thus was not prepared to participate in the discussion. Discussing her child’s classroom behavior was a topic she was not prepared to discuss.

> Those were the things that took us by surprise at the meetings and would set us off guard. Because we weren’t really going there to talk about what would be typical classroom behavior or something that could be dealt with on a day-to-day thing, and it wasn’t a part of the IEP or agenda.

Likewise, Jaimie also preferred when paperwork was sent home beforehand. She said it helped her to participate by preparing her emotionally. She noted, “I liked it when they sent the paperwork home ahead of time…and then I would just write my own questions on the side. So then, I wouldn’t be too emotional to not ask them because I couldn’t remember.”

Missy stated increased understanding of what will be addressed increased her participation; she liked having a listed agenda so she could see what was coming next. She liked “having certain number of minutes for each agenda item with a space for ‘other’ so that you can get all the information shared.”

Five participants conveyed that being a part of scheduling the IEP conference and selecting the time of day when the meeting was held was essential for their engagement and participation. Erica was perturbed when IEP conferences were scheduled without her input: "They'd just schedule a meeting and say, 'His IEP meeting is set for this time—would you like to attend?' I'm like, 'That doesn't work for us. So we need to look at some other options because we both want to attend.'" The time of day when the IEP conference was scheduled impacted participation. Participants expressed that meetings scheduled before or after school did not allow ample time for collaboration with general education staff.

Four participants expressed a need for personal contact encompassing personalized phone calls, communicating with one school contact versus a large team, and being connected to other parents. Rachel suggested more personal contact by having someone from the school call parents before their first scheduled IEP conference so they know what to expect.

Missy added, "If I had had a conversation with the school psychologist or somebody beforehand to kind of prep me, I would have felt better and I would have been able to prep my husband." Often, initial IEP conferences to discuss evaluation results or initial placement decisions have numerous professionals involved. When Jaimie reflected on what would improve parental experiences she shared, "I think to be more sensitive to parents it would be nice to just talk to one person because everybody writes a report." Missy added, "I do not think school systems are very respectful of parents' emotions. We're expected to process, and so we have to get through all this paperwork because by law we have to, at the risk of losing families."

Experiencing a first IEP conference and having a child with a disability can be isolating for parents. June believed connecting parents with other parents might be helpful as a support system.

> Connecting parents with other parents who have gone through the same things would be helpful. If there are parents who have gone through it, that could give feedback and what to be prepared for. It is easier if we have got other parents that have gone the same things that can kind of help and guide. They can help you navigate this process.

Patti agreed such supports might be beneficial. She indicated everybody should have an advocate on their end because when her son was first identified she did not have the knowledge or have somebody telling her what the laws were. Rachel said, "I am a person who loves to talk and loves to meet people. If I could have connected with other parents who are going through the same thing I think it would have been better for me." Sarah said the key for her was to get assistance outside of school. She claimed she had to go outside of the school for assistance, which she found in therapies and social skills groups.

Susan focused on having a personal connection with someone from the school system. She said, "Having a consistent IEP case manager is helpful as long as the kids and that case manager get along."

Karen, who works in the special education field, thought schools send inexperienced teachers out to meet with families, and they do not know what services and resources are available in the community. She also claimed some teachers are afraid to talk about autism. She shared:

> We have to do something different for parents just coming into the system because it sets the tone for all of their experiences. So, if you do not have good early experiences in kindergarten, I am going to tell you that they are never going to trust the school at the elementary level and they are not going to trust you at the high school level.

The Future

Many parents of children with disabilities spend a considerable amount of time contemplating what the future may hold for their child. Parents are concerned about their child's

inclusion in society, including financial and physical independence. Others are concerned about the child's education, the ability to acquire a profession and have independence, while still others are concerned about where he or she will live, and whether their child's future would entail having a family of their own (Heiman, 2002).

Parents involved with this study had a variety of experiences with the IEP process and a variety of concerns for their children. Nine participants explicitly expressed their thoughts and hopes for their child's future, embracing positivity and hopefulness when they discussed the future endeavors of their children with disabilities.

Karen's son is in kindergarten. He is currently serviced under the autism classification and is also delayed cognitively. Karen reflected that she is a very religious person and she actually believes that God doesn't close one door without opening another door. She continued, "I just feel like it's a different road for me to take. It's not the road I thought I was going to take, but it's just a different road." When reflecting on what Max's future holds she said, "I think he'll have a normal, successful life for who he is. I can accept him for where he's at."

Karen has some safety concerns that Max gets so obsessed with what he is doing, he doesn't know when to stop. Karen wants him to learn how to stop while out in public and follow directions so that he's safe. She laughed as she indicated they are trying to whistle and do some different things with him because he's five and he's nonverbal. Karen has accepted they are not going to fix him. "He is whom [*sic*] he is. He is going to have this disability his whole life, and I know that."

Jordan's son, Allen, has almost completed his second grade year and is looking forward to third grade. Jordan and her husband have talked about Allen's future and if he will ever get married and have children. Jordan commented,

> Now it's just Allen. It's just who he is, and he's great the way he is. And he's hilarious and he's super smart. And we still try to encourage him to talk to other children and we hope that it will get better as he gets older. He's great. I'm happy with the kid that I have and I'm blessed with the kid that I have. And I couldn't ask for a better one.

Patti explained, "I have fully accepted Ryan for who he is. I'm perfectly fine with it." Her dream for him is to go to college. She wants him to live on campus and just have a typical college experience. She said, "Whether that's going to happen or not, I don't know at this point." She reports that he has shown some interest in computer technology and thinks it would be perfect for him. He remembers things and he loves tinkering around on the computer.

Missy, a mother of a senior who has the "other health disability" classification contributed, "I gotta kinda say senior year was a good year for us. I worried a lot about whether he'd make it in college or life. Who'd be his friends? Would I be stuck with him forever?" She continued, "But his special education teacher was the best and I'm confident he'll be fine. He'll have friends, he'll be able to get a job, and maybe get married if that's what he wants."

Erica's son is in high school and is Deaf. She reported that his future plans are to attend college.

> You know, I'm always thinking about his future. You know? But just wanting him to get what everybody else gets—as far as education—and have the same opportunities that other typical children have. I want to make sure we're doing whatever we can to give him the best that can have, so he can really reach his fullest potential.

Another participant, Sarah, said, "[Nathan's] doing awesome. He is planning on attending Iowa State to study mechanical engineering. We're not quite sure that's the route he should take, but he likes it."

Tom, whose son has a visual impairment, believed that his son would be successful. He explained that his son would probably attend the transition program the district offers. Tom shared that it is difficult because his son is a twin and his sibling is planning on attending a four-

year college. Tom reiterated his concern about the future and what it holds for his son. He said, "I hope that he can one day live independently and not in our basement or something."

Sharon said she has realistic expectations for Denise. At the last IEP meeting she explained that she had to ask what was more important, "For Denise to fill out a job application or for her to get dressed?" She continued, "She will never, ever do a job application by herself. But I shouldn't have to worry about her not being able to button her coat or zip up a pair of pants. That's important."

Dana reported that her 16-year-old son with Down syndrome is very active. He's on the adaptive soccer and softball team. He attends the regular youth group at church. She contributed, "We've just always tried to say, 'Hey, what do we want to do in life?' And just make it happen for him."

Summary

In summary, participants shared the feelings they experienced during and after the IEP conferences. I described how parents analyzed the conference, how they were often reminded that their child has a disability, how they evaluated their communication and satisfaction with their role in the IEP conference, and their feelings after the conference. I also identified parents' impressions for increasing parental participation and engagement in the IEP conference. Finally, I described parents' hopes for the future endeavors of their child with a disability.

I next present analysis for findings in Chapter 6, utilizing the grief and loss model ideologies of Kübler-Ross (1969), Lamb (1988), and Kübler-Ross and Kessler (2005).

Analysis: The Final Stage—After the Conference

In analyzing parental feelings after the IEP conference while employing the Kübler-Ross and Kessler foundation of grief and loss, I found in the final stage of the IEP process parents moved between different emotions in the grief and loss continuum. Kübler-Ross (1969) and Kübler-Ross & Kessler (2005) recognized individuals may move back and forth through different emotions and between stages until they resolve their crisis. While this can be achieved in a linear process, it is not likely.

Final Stage: The Grief and Loss Model

The emotions associated with acceptance and hope comprises the final stage of grief. According to Haley, et al. (2013),

> At this stage, parents may be at a point where they recognize the reality of their child's disability and have come to terms with that understanding. Parents begin to feel they can cope. Parents may begin to join support groups and may also develop outside relationships that are not focused on their child's disability. (p. 239)

"The underlying thought is 'We may not like the hand we were dealt, but we can do this.' (Bolden, 2007; Boushey, 2001; Evans, 1976; Friehe et al., 2003)'" (as cited in Haley, et al. 2013, p. 239).

Reminders of the diagnosis. During this stage of the IEP process, parents may be reminded their child has a disability and have to relive the emotions they felt during the other stages of the grief and loss model. Additionally, parents may have negative memories from their own educational experiences. When parents expressed they were "stressed out" or "processed," or thought about whether they "should have said this or should have asked that," they may be experiencing the emotions of guilt, depression, or isolation from the intermediate stage of the grief and loss model. Boushey (2001) wrote, "No matter how much I read on the subject, I felt

behind. No matter how many conferences on autism that I attended, it wasn't enough. My son was growing up right before my eyes, and I felt that for every step he took forward, I needed to take two to stay caught up" (p. 29).

Factors that influence quality of interactions. Parents had indeed passed through Kübler-Ross' five stages of grief and reached the final stage of acceptance and hope when they expressed that they were satisfied when they knew the IEP was going to be followed and began to trust the school personnel. Remarks such as "I just really feel like the school is doing what they can to support us," and "I feel like he's making gains. I'm really okay with what school is doing. I trust school" demonstrate they were able to come to terms with the grieving process.

The future. Additionally, 10 parents in this study were able to achieve final stages of the grief and loss cycle. Those participants recognized the reality of their child's disability and had come to terms with that reality (Figure 1). They experienced emotions of acceptance and hope when discussing their child and his or her future. Six participants expressed the specific emotion of acceptance when they made statements such as "I have fully accepted Ryan for who he is. I'm perfectly fine with it," and "Now it's just Allen. It's just who he is, and he's great the way he is. He's great. I'm happy with the kid that I have and I'm blessed with the kid that I have." Dana expressed both acceptance and hope when she shared, "He is very active. He is on the adaptive soccer and softball teams. He attends the regular youth group at church. We've just always tried to say, 'Hey, what do we want to do in life?' And just make it happen for him." Four participants expressed hope for their child's future. This was evident when Missy said, "I'm confident he'll be fine. He'll have friends, he'll be able to get a job, and maybe get married if that's what he wants."

Chronic Sorrow

Finally, four participants did not indicate they were able to achieve the final stages of the grief and loss cycle consisting of acceptance and hope. Two participants, Kris and Rachel, had medical diagnoses, and Jamie and June had educational determinations for their children. Rachel, Jamie, and June, had children diagnosed with Autism Spectrum Disorder, and Kris's son, had a visual impairment.

Analysis revealed participants who did not reach the acceptance and hope stage may be experiencing chronic sorrow. Olshansky (1962), first introduced the term "chronic sorrow" when he described the normal pervasive psychological response in the suffering of parents dealing with children with disabilities. He observed parents of children with significant disabilities suffered from chronic sorrow throughout their lives as a reaction to both the loss of the expectations they had for the perfect child and the day-by-day reminders of dependency. Chronic sorrow contrasts with the grief and loss model of Lamb (1998), and Kübler-Ross and Kessler (2005) in that chronic sorrow is defined as a normal grief response associated with an ongoing living loss that is permanent, progressive, recurring, and cyclic in nature (Gordon, 2009). Both Damrosch and Perry (1989) and Griffin and Kearney (2001) found it was common for parents of children with disabilities to feel chronic sorrow because the expectations each parent has for the child are no longer being met, and the hope for a "whole" or "normal" child is fantasy.

Participants who may be experiencing chronic sorrow (Olshansky, 1962) reported particularly emotional and exasperating experiences at IEP conferences. June did not agree with the classification the school was using and walked out of the IEP conference. She exclaimed, "I walked out of that conference meeting in tears…I was like; this is ridiculous." Likewise, Jaimie also did not agree with the disability classification, "I hate the classification. They're just really

hard, especially the autism/Asperger one." June remained irritated that the outside agency gave a specific diagnosis and the school did not. She continued to grapple with accepting that her son had special needs. Additionally, Jaimie, Rachel, and Kris reported emotional IEP conferences. Kris cried at every IEP conference. She remarked, "Usually, I can get out the door and make it to the curb before crying." This profound sadness and loss felt by parents manifested as anger, loss, and denial may be the cyclical reaction to chronic sorrow (Olshansky, 1962) (*Figure 4*).

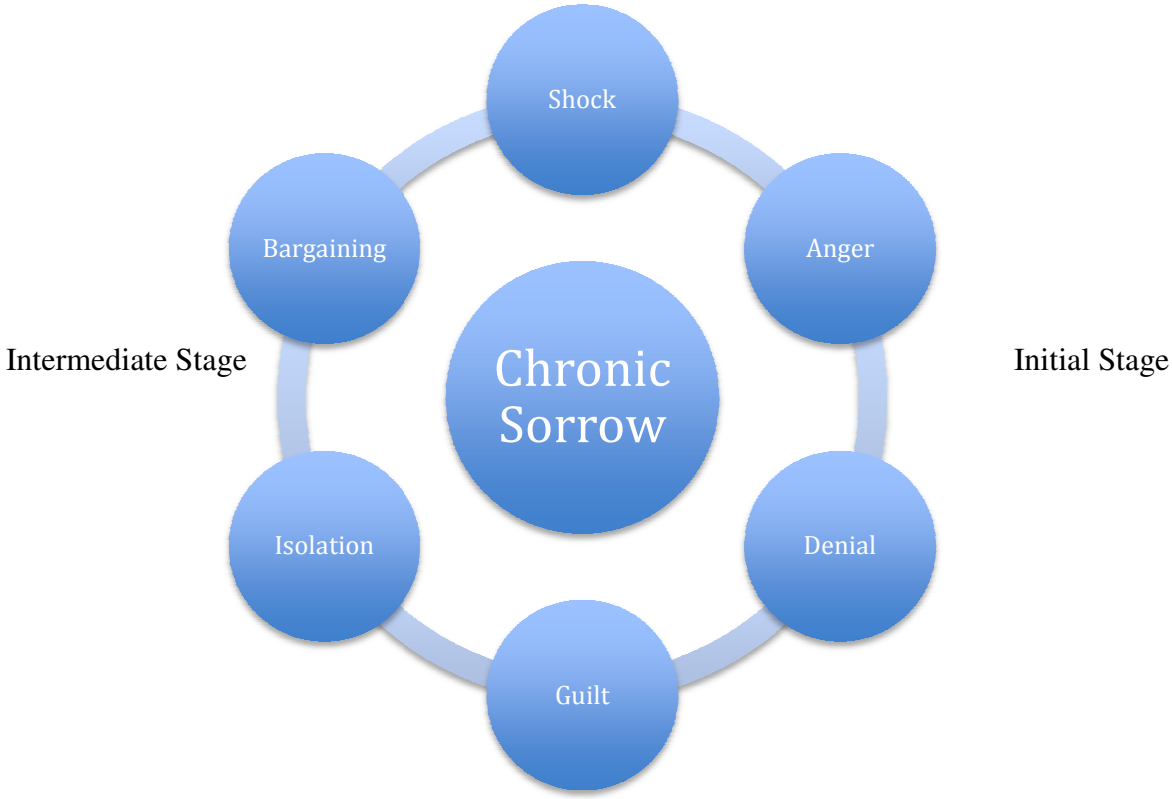

Figure 4. Parental Experiences with Chronic Sorrow (Olshansky, 1962).

Acceptance and hope and years involved in special education. Parents who reached the acceptance and hope stage of Küble-Ross' five stages of grief had a variety of years involved in special education, ranging from two years to 16 years. Karen and Jordan had the least number

of years involved in special education with just two years, while Sarah, Erica, Sharon, and Dana had between 13 and 16 years of involvement in special education. Patti, Missy, and Tom each had 6, 7, and 11 years respectively of involvement in special education. For the parents who reach the acceptance and hope stage of Küble-Ross' five stages of grief, the number of years that a parent is involved in special education is not a factor.

Chronic sorrow and years involved in special education. Parents who may be experiencing chronic sorrow (Olshansky, 1962) had between four and eleven years of involvement in special education. June spent the least amount of time involved with special education with just four years, while Kris spent the greatest amount of time with 11 years. Rachel had five years, and Jamie had 10 years of involvement in special education. The number of years involved in special education does not make a difference in whether a parent reaches the final stage of acceptance and hope or experiences chronic sorrow (Olshansky, 1962).

Summary

I analyzed parental reactions during the final stage of the IEP process, the point at which parents have experienced the IEP conference and have an impression of their satisfaction with both the meeting and their participation. In the final stage of the grief and loss model, parents experience emotions of acceptance and hope, and may move back and forth between different emotions on the grief and loss continuum.

The data and subsequent analysis revealed parents who have reached the final stage of the grief and loss model—acceptance and hope—reported having positive reactions to the IEP conference. Parents in this stage of the grief and loss model reported feelings of trust, the sense of being heard, and positive communication with school personnel. They also experienced hope for their child's future endeavors. Those parents experiencing chronic sorrow (Olshansky, 1962)

reported particularly emotional and exasperating experiences at IEP conferences, were not as engaged with school personnel during the conference, and had less productive conferences.

In the final chapter, I provide a summary of my findings, describe implications for the field, and recommend areas for further research.

Chapter 7: Summary, Implications and Recommendations

I examined the experiences of parents attending individual educational plan (IEP) conferences to understand how these experiences affected their ability to participate and make decisions regarding their child's educational goals and related plans. I identified parental experiences in three stages corresponding with the grief and loss model of Lamb (1998), and Kübler-Ross and Kessler (2005). The stages consisted of: the initial stage, in which I examined the initial referral for special education services and parental feelings accompanying that experience; the intermediate stage, where parents first encounter school personnel at the IEP conference; and the finale stage of the IEP process, where I noted parental impressions after the IEP conference and their expectations for their child's future. In this chapter, I describe my findings and make recommendations regarding parental participation in the IEP conference. I then recommend factors influencing communication and partnership during the conference. I end this chapter with recommendations for further research. First, I review my general and supporting research questions and findings.

I adopted the following question to guide my study: How do parents experience the IEP conference as advocates for their children and partners involved in planning and supporting their children's educational program? I found parents reacted to the IEP conference differently based on the stage of grief and loss they were experiencing. This gives rise to a second question: How do these experiences impact their participation with regard to their child's educational plan and program? I found that attending IEP conferences was an emotional undertaking for parents. Participants described feeling anxious, nervous, or worried before their scheduled conferences. For some, this occurred before every conference. I used the following questions to support my two general questions:

1. How does the experience of the IEP conference affect parent views of school personnel and influence their decision to actively participate in planning and supporting their child's educational plan and program? Parental experiences and engagement were dependent on the stage of grief and loss they were working through.
2. How does the nature of the communication with school personnel promote or hinder parental participation in the IEP conference? I found parental perceptions of IEP conferences were emotionally based, and dependent on the stage of grief parents experienced at the time of the conference. Additionally, I found parents indicated positive experiences when school personnel conveyed positive messages regarding their child and when they felt school personnel genuinely cared for their child.
3. How do parents experience and evaluate their communication interactions with school personnel during the IEP conference? I found parents who had reached the final stage of acceptance and hope experienced positive collaboration and were more engaged in the IEP conference then those who were experiencing chronic sorrow (Olshansky, 1962). Parents experienced a wide range of emotions as they participated in the IEP conference. These emotions can be related to the emotions individuals experience in the grief and loss model or chronic sorrow (Olshansky, 1962). This study revealed parental experiences, participation, and engagement in the IEP conference were dependent on what stage of the grief and loss cycle they were experiencing.

I next describe my findings and make recommendations for how school personnel can collaborate with families experiencing grief and loss or chronic sorrow (Olshansky, 1962).

Findings and Recommendations

Parents come to the school system with unique backgrounds, and experience a wide array of emotions as they become involved in the IEP conference. All participants identified at least one of the emotions of shock, anger, and/or denial when their child was referred for a special education evaluation. Of the two pathways - a medical diagnosis and subsequent educational determination, or an educational determination exclusively - I found more denial and anger directed at the school for those with an educational determination. This may indicate parents who receive a medical diagnosis for their child were more prepared for the educational determination of eligibility for special education services. This early indication of the emotions of anger and denial set the stage for problematic communication and collaboration, and potential adjustment issues during future IEP conferences. Additionally, the number of years parents were involved in special education services did not make a difference for those experiencing chronic sorrow (Olshansky, 1962); however, those with considerable experience, and less doubt about the medical condition, achieved better degrees of integration and satisfaction.

The study revealed the need for enhancing family involvement and helping parents through the emotional distress of being notified their child is in need of special education services. School personnel in this study were not trained to recognize or deal with parental reactions or emotions, which led to parents feeling disenfranchised. I recommend training in the areas of parental grief and loss for individuals in special education teacher licensure programs, and required professional development for licensure renewal. Special educators should also recognize that acceptance of a disability may take years, and for those parents experiencing chronic sorrow (Olshansky, 1962) they may never reach acceptance. Additionally, I recommend IEP conferences include guidance counselors, school psychologists, or social workers trained to

help parents deal with emotional reactions to the process, especially during the initial IEP conferences where school personnel discuss special education eligibility.

School professionals need to understand that at the time of the IEP conference parents may be experiencing a wide array of emotions, including shock, denial, anger, guilt, sadness, or disappointment. I recommend school professionals be trained to recognize the signs of grief and loss, and adjust their approach to accommodate these emotions. They must understand experiencing grief and loss is a natural response to coming to terms with the loss of the child expected before the disability identification. School professionals may assist parents by allowing them an opportunity to experience these emotions and not minimize or deny their feelings.

Another recommendation would be to connect families of students with disabilities with other families. Throughout the study, participants experienced emotions of shock, isolation, confusion, depression, blame, and stress. The benefits of sharing these feelings with other parents going through similar emotions may enhance the partnership needed between parents and school personnel.

When a student is referred for a special education evaluation, school districts might be required to provide information regarding parent support groups as an element of the special education referral process. Additionally, school districts should be offering parent support groups with district mental health professionals or allow outside agencies to use district facilities to meet with parents.

Various factors enhanced or hindered communication and participation in the IEP conference. I describe these factors and recommend practices for promoting parental participation.

Participants indicated positive experiences and satisfaction during IEP conferences when school personnel conveyed positive messages regarding their child and when parents felt school personnel genuinely cared for their child. Specific messages regarding strengths or idiosyncrasies of the student and personalized stories also had positive effects on parental participation.

Participants evaluated communication interactions with school personnel positively when they felt they were being heard and were able to provide input. Additionally, parents specifically stated that words of affirmation and validation regarding the efforts they took at home with their child made them feel positive about their communication and interactions at the conference.

Final Stage

The study revealed parents who had reached the final stage of the grief and loss model—acceptance and hope—reported having positive experiences and communication with school personnel during the IEP conference. Parents reported feelings of trust, being heard, and positive communication with school personnel. Those parents experiencing chronic sorrow (Olshansky, 1962) reported particularly emotional and exasperating experiences at the IEP conference, were not as engaged with school personnel during the conference, and had less productive conferences.

I recommend continued training for educational professionals in order to help those parents of a child with a disability experiencing grief, loss, and chronic sorrow (Olshansky, 1962). Additional recommendations include establishing partnerships and resources to connect parents to support groups for parents of students with disabilities, and those experiencing grief and loss (*Figure 5*).

Recommendations For Practice

Conducting this study permitted me to have a profound appreciation of parents' perspectives, experiences, and engagement in the IEP conference. The information gleaned from this study has changed my practices as the director of special services of a growing suburban school district. Our organization has changed the way we conduct our staff meetings, our dialogue, and the language we use. We no longer characterize parents who may be experiencing grief and loss as "difficult parents." We listen more to parents. As education professionals we need to ask questions about parents' experiences and try to understand what life is like for them, their child, and their family. We acknowledge that meeting the needs of a child with a disability can be extraordinarily difficult, frustrating, and emotionally draining for parents. During IEP conferences we may disagree with parents, but we accept that it is the responsibility of parents to advocate for what they believe is in the best interest of their child.

Additionally, the special education department has implemented a "Parent University" with the primary goal of supporting parents by connecting them to services available to them from the county or other outside agencies. This endeavor includes regularly scheduled educational workshops on issues identified by parents as important to them, and a resource fair with topics including mental health, stress and anxiety, and grief and loss.

Summary

In summary, parental participation, satisfaction, and engagement in the IEP conference were dependent on the stage of grief and loss parents were experiencing at the time of the conference. In this study, some parents of children with significant disabilities never reached the final stage of acceptance and hope in the grief and loss model. Parents who had reached the final stage of the grief and loss model experienced positive IEP conferences, and generally positive

collaboration with school personnel. Parents who were experiencing chronic sorrow (Olshansky, 1962) had particularly harrowing IEP conferences as they ebbed and flowed through the sorrow which surfaced and resurfaced throughout the parents' life long experience.

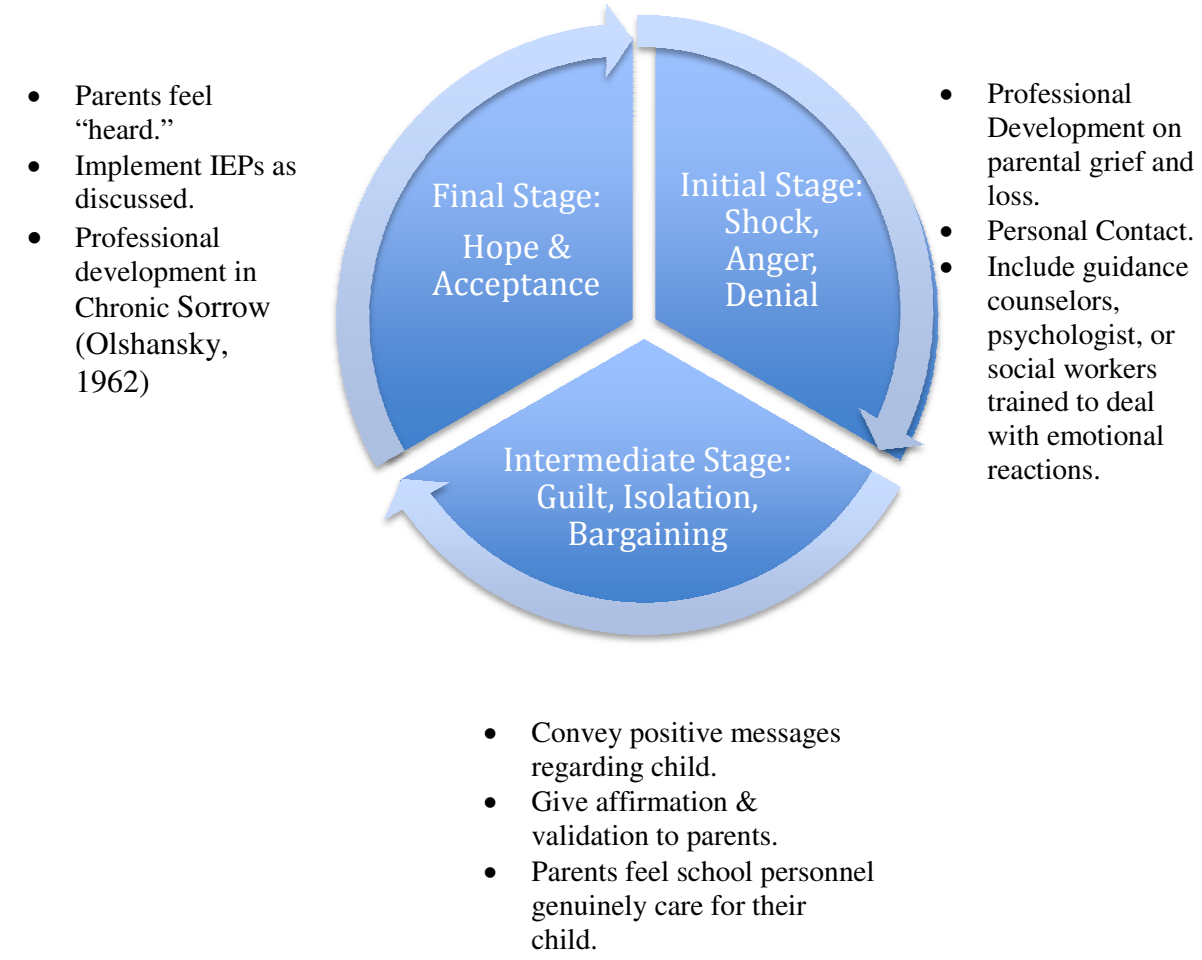

Figure 5.
Recommendations to Assist Parents in the Grief Journey.

Recommendations for further Research

Previous research focused on the components of the IEP conference such as language, due process compliance, and actions of school personnel. Few studies focused on the emotional

context of IEP conferences specific to grief, loss, and chronic sorrow (Olshansky, 1962). This study confirmed the relationship between grief and loss and parental satisfaction with the IEP conference. Future research may want to focus on the continuation of the current study, and incorporate special education teachers' perspectives, and the perspectives of fathers of children with disabilities. Additionally, studies regarding chronic sorrow (Olshansky, 1962) and its educational implication are limited. As more children are diagnosed with disabilities, research on the implications of chronic sorrow (Olshansky, 1962) and the IEP conference need further exploration.

This study revealed more emotions of anger and denial directed at school officials for those with an educational determination than those with a medical diagnosis. Further research considerations may include conducting a study on the effects of the type of disability or medical diagnosis and how parents experience grief and loss or chronic sorrow (Olshansky, 1962) during the IEP conference. Additional studies may focus on why those with a medical diagnosis seem better prepared for the educational determination for special education services than those who receive an educational determination exclusively. Future studies may want to examine if medical professionals inform parents about disability differently than educational professionals, and the effects that has on grief and loss.

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APPENDICES

Appendix A: IRB Approval

Dear Kevin,

Re: IRB Proposal #: B10- 210- 02 - A Case Study of Parental Experiences and Engagement in the Individual Educational Plan (IEP) Conference
Researcher: Kevin Witherspoon
Advisor: Dr. Sarah Noonan

Full Status Approval

Your application for your proposed research involving human subjects has been reviewed by the Institutional Review Board of the University of St. Thomas and been given Full Approval Status. Your application has satisfied all of the criteria necessary for full status. This means that you may proceed with your research immediately. This is your official letter of approval.

Please place the IRB log number on all of your future correspondence regarding this protocol.

Please note that under IRB Policy principal investigators are required to report to the IRB for further review when changes in the research protocol increase the risks to the rights and welfare of human subjects involved in the study and /or I n the event of any adverse episode (e.g. actual harm, breach of confidentiality) involving human subjects.

Thank you for all of your work.

Please contact me if I can be of further assistance.

Best wishes as you begin your research.

Eleni Roulis,Ph.D.
Institutional Review Board Chair
2115 Summit Avenue #5037
St. Paul, MN 55105
Aquinas 314A
651-962-5341
e9roulis@stthomas.edu

Appendix B: Agency Consent Letter

Richard J., Ph.D.
Assistant Superintendent for Curriculum and Assessment

5/9/2010

Kevin Witherspoon
Assistant Principal
High School

Dear Mr. Witherspoon:

I am writing to acknowledge that you have requested our office to review an application to conduct your dissertation study titled, "A Case Study of Parental Experiences and Engagement in the Individual Educational Plan (IEP) Conference" within the Suburban School District. It is our understanding from the proposal that this is a qualitative study that aims to examine the experiences of parents during the IEP conference to understand how effective communication might improve the collaboration and advocacy needed to serve special education students.

Further, it is our understanding that you will not recruit parents of students who attend High School, but will ask for participants via the special education department or the Special Education Advisory Council. All participants who sign a consent stating agreement to participate with an understanding there is no obligation to do so, that they may discontinue at any time, and that there are no negative outcomes for refusal to participate and that no negative outcomes would occur for their child's programming for willingness to participate or not. A final copy of the consent letter should be sent along with the final IRB approval from St. Thomas.

Since the primary contacts for your study are parents this application meets exempt status. However, our district does require a final submission to our Research, Evaluation, and Assessment department of final IRB approval from the University of St. Thomas prior to the initiation of any research activities commence. In addition, each project that runs within our district requires an internal sponsor. I am asking Ms. M. our Director of Special Education to be the primary contact during the course of the study. Please continue to collaborate with her office on project timelines and requests. We wish you well with your Dissertation work and request at the end of the project our REA Department does request a brief executive summary to be sent as a condition of approval.

Sincerely,

Richard J., Ph.D.
Assistant Superintendent
of Curriculum and Assessment

Appendix C: Electronic Mail to Participants

Recruitment Email Script

Dear Colleague:

I am conducting a study about parent participation in the IEP Conference for my dissertation through the University of St. Thomas. I was wondering if it would be possible to attend a Special Education Advisory Council meeting to talk with parents and ask for volunteers to participate in my study. The ultimate goal of my research is to create equal participation of parents with school professionals during the IEP conference. I would ask that parents attend an interview for 60 to 90 minutes and be open and honest in their answers. Results from the interviews will remain confidential.

I look forward to hearing from you about the possibility of talking with your Advisory Council. Please contact me at your earliest convenience. You may also contact me by phone at XXX-XXX-XXXX.

Sincerely,

Kevin Witherspoon

Dear Colleague:

I am conducting a study about parent participation in the IEP Conference for my dissertation through the University of St. Thomas and would like you to participate in my study. The ultimate goal of my research is to create equal participation of parents with school professionals during the IEP conference. To participate, I would that you attend an interview with me for 60 to 90 minutes and be open and honest in your answers. Results from the interviews will remain confidential.

I look forward to hearing from you about the possibility of your participation in an interview. Please contact me at your earliest convenience. You may also contact me by phone at XXX-XXX-XXXX.

Sincerely,

Kevin Witherspoon

Appendix D: Postcard Describing Research

Please participate in a study of parental experiences at the IEP conference

My name is Kevin Witherspoon and I am conducting a study about parental experiences at the Individual Educational Program (IEP) conference. I invite you to participate in this research.

To participate in this study you will be asked to have a face-to-face interview with me for approximately one hour at ***"your"*** convenience. **All records from this study will be kept confidential.**

If you would like to participate or have any questions, please contact me.

Appendix E: Initial Interview Questions

General Statements/Interview Guide for Parents

1. We are going to start out with some background information, tell me about your son or daughter.

2. Please tell me a little bit about your child and your experiences in special education.

3. Can you tell me about the early experiences when your child was first identified. What was that like for you?

4. Let's talk about some historical kinds of things, can you remember back to that very first IEP conference, what was that like for you?

5. Let's talk about your last IEP conference, what were you thinking while this was going on? What was it like for you?

6. Were the goals and objectives on the IEP shaped by your input? Did you get what you needed?

7. Please tell me what makes you feel satisfied when you leave an IEP meeting?

8. What makes you feel like an equal partner?

9. How does the relationship you have with the school change how you feel going into or leaving a meeting?

10. What else would you like me to know?

Appendix F: Transcriber Confidentiality Agreement

TRANSCRIBER CONFIDENTIALITY AGREEMENT
UNIVERSITY OF ST. THOMAS

[Insert Title of Study]
[Insert IRB log number when assigned]

I, ___Judy Graf_____, agree to transcribe data for this study. I agree that I will:

1. keep all research information shared with me confidential by not discussing or sharing the information in any form or format (e.g., disks, tapes, transcripts) with anyone other than Kevin Witherspoon, the primary investigator of this study;
2. keep all research information in any form or format (e.g., disks, tapes, transcripts) secure while it is in my possession. This includes:
   - using closed headphones when transcribing audiotaped interviews;
   - keeping all transcript documents and digitized interviews in computer password-protected files;
   - closing any transcription programs and documents when temporarily away from the computer;
   - keeping any printed transcripts in a secure location such as a locked file cabinet; and
   - permanently deleting any e-mail communication containing the data;
3. give all research information in any form or format (e.g., disks, tapes, transcripts) to the primary investigator when I have completed the research tasks;
4. erase or destroy all research information in any form or format that is not returnable to the primary investigator (e.g., information stored on my computer hard drive) upon completion of the research tasks.

Judy Graf
Signature of transcriber

5-04-10
Date

Kevin J. Witherspoon
Signature of researcher

5/04/10
Date

Appendix G: Participant Consent Form

CONSENT FORM
UNIVERSITY OF ST. THOMAS

Active and Equal Team Members or Recipients of Information: Divergent Perspectives on the IEP Conference

[IRB log # B10-210-02]

I am conducting a study about parent participation in the Individualized Educational Program (IEP) conference. I invite you to participate in this research. You were selected as a possible participant because you either have a child with an IEP and have attended at least one IEP conference or are a special education administrator. Please read this form and ask any questions you may have before agreeing to be in the study.

This study is being conducted by: Kevin Witherspoon, University of St. Thomas Department of Educational Leadership.

Background Information:

The purpose of this study is: To explore how the degree of parental knowledge about their child's disability as well as their participation during the IEP conferences influence the educational plans and goals ultimately adopted by the educational team. What characterizes genuine parental participation in the IEP conference, and what do parents and professionals expect from each other during the IEP conference. The ultimate goal of this research is to create equal participation of parents with school professionals during the IEP conference.

Procedures:

If you agree to be in this study, I will ask you to do the following things: attend an interview with myself and be open and honest in your answers. The interview will be audiotaped and will last 60 to 90 minutes. Results of the interview will remain confidential and your name and other personal data will not be used to identify you.

Risks and Benefits of Being in the Study:

This is a non-invasive study with no foreseeable risks to participants.

The direct benefits to you for participating are: There are no direct benefits to participating in this research project.

Confidentiality:

The records of this study will be kept private. In any sort of report I publish, I will not include information that will make it possible to identify you in any way. Research records will be kept in a locked file; I am the only person who will have access to the records. I will be the only person that will have access to audiotapes of the interview. They will be destroyed on December 1, 2011.

Voluntary Nature of the Study:

Your participation in this study is entirely voluntary. Your decision whether or not to participate will not affect your current or future relations with the University of St. Thomas. If you decide to participate, you are free to withdraw at any time without penalty. Should you decide to withdraw data collected about you it will be kept by the researcher and used in aggregate with other data collected.

Contacts and Questions

My name is Kevin Witherspoon. You may ask any questions you have now. If you have questions later, you may contact me at xxx-xxx-xxxx or Dr. Sarah Noonan xxx-xxx-xxxx. You may also contact the University of St. Thomas Institutional Review Board at 651-962-5341 with any questions or concerns.

You will be given a copy of this form to keep for your records.

Statement of Consent:

I have read the above information. My questions have been answered to my satisfaction. I consent to participate in the study. I give my permission to having the interview audiotaped.

_____ _____

Signature of Study Participant **Date**

_____ _____

Signature of Parent or Guardian (If applicable) **Date**

_____ _____

Signature of Researcher **Date**